



## **Section II: Site-Specific Cancers**

- Chapter 6: Breast
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## CHAPTER 6. Breast Cancer

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## BREAST CANCER

### IMPORTANCE OF BREAST CANCER FOR CANCER PREVENTION AND CONTROL

The greatest impact on reducing the number of years lost to cancer will come from progress against common cancers such as breast cancer. Nationally, female breast cancer is the most common cancer among women, comprising an estimated 31% of new cancer cases and causing 15% of cancer deaths in U.S. females for 2002 (1). (Information about breast cancer in males can be found by contacting [www.nci.nih.gov](http://www.nci.nih.gov).) In the National Cancer Institute's (NCI) *Annual Report to the Nation*, breast cancer was cited as the most common cancer diagnosed among women in all five racial and ethnic populations studied (2). In 1998, breast cancer caused 790,000 person-years of life lost, ranking second after lung cancer (2,272,000) (3). Between 1980 and 1998 the rate of new cases of late-stage breast cancer remained relatively stable, indicating that the impact of breast cancer screening must be examined further. According to the *Cancer Progress Report* of the National Cancer Institute, breast cancer in women has been identified as a major cancer on the rise and one that therefore warrants greater efforts at control (3).

The Breast Cancer Workgroup of the Task Force on Cancer Prevention, Early Detection and Treatment has compiled evidence to indicate that breast cancer is also a key area to address in New Jersey. As will be shown later in this chapter, invasive breast cancer incidence among New Jersey females continues to increase. The decline of breast cancer mortality is not consistent across all populations in New Jersey. Effective breast cancer early detection techniques are not being used consistently across all populations in New Jersey. Below is a brief discussion of

the known risk factors for breast cancer and some of the means available to detect and control the disease.

The causes of breast cancer are not all known; however, some risk factors are well recognized. The risk of breast cancer increases greatly with age. The risk factors also include family history, familial cancer syndrome, as well as reproductive and hormonal factors such as early menarche (early onset of menstruation), late menopause, late parity (bearing children late), and nulliparity (not bearing children). High educational and socioeconomic levels are linked with greater risk, probably due to their association with the reproductive risk factors. Jewish women are also known to be at higher risk of breast cancer, while black women have lower rates of the disease than do white women. Certain types of benign breast disease (fibrocystic, fibroadenoma), obesity after menopause, and moderate to heavy alcohol consumption (3 or more drinks per day) also are associated with breast cancer. Very high doses of radiation, such as that used in radiation therapy, have been shown to cause breast cancer. Long-term use of estrogen replacement therapy after menopause may increase the risk of breast cancer. Some recent studies suggest a possible increase in breast cancer before the age 45 among women who used oral contraceptives for a long time or who started oral contraceptive use at an early age. Other factors that may be associated with breast cancer are a lack of physical activity and a diet high in fat. Other risk factors, such as pesticide and other chemical exposures that mimic or modify the action of estrogens and gene-environmental interactions are being investigated (4-6).

Breast-Self-Examination (BSE), Clinical Breast Examination (CBE), and mammography are methods for screening and early detection of breast cancer. Although many organizations recognize these three screening techniques, guidelines for frequency of testing differ by organization (7-10). For more information about screening guidelines for breast cancer see Appendix F.

Regular use of mammograms can reduce the chances of dying from breast cancer. Randomized clinical trials have demonstrated a 30% reduction in breast cancer mortality in women aged 50 to 69 years who are screened annually or biennially with mammograms (5). For women in their 40s, the risk can be reduced by about 17%. For women aged 70 and older, mammography may be helpful, although firm evidence is lacking (10). Since implementation of the Mammography Quality Standards Act in 1994, all U.S. mammography centers must be certified by the Food and Drug Administration (FDA) (5). A complete list of all certified mammography centers in New Jersey can be found at <http://www.fda.gov/cdrh/mammography/certified.html>. The six currently FDA-approved digital mammography centers in New Jersey can be found at [www.hersource.com](http://www.hersource.com).

In terms of primary prevention, tamoxifen, a selective estrogen-receptor modulator, has been shown to reduce breast cancer incidence among women at elevated breast cancer risk. Five-year adjuvant treatment of tamoxifen has also been shown to significantly reduce recurrence of secondary malignancies in early stage breast cancer patients (11;12). The American Society of Clinical Oncology conducted a technology assessment of tamoxifen and concluded that, for women with a defined five-year projected risk of breast cancer equal to or greater than 1.66%,

tamoxifen (20 mg/day for up to five years) may be offered to reduce risk (13;14). However, tamoxifen may also increase the risk of contracting other serious disease, including endometrial cancer, stroke, and blood clots in veins and in the lungs (14). Women concerned that they may be at increased risk of developing breast cancer should talk with their doctor about whether to take tamoxifen to prevent breast cancer.

Genetic testing for breast cancer is relatively new. The “breast cancer gene,” BRCA1, was identified in 1994 (15) and BRCA2 in 1995 (16). A positive on a mutation test result indicates enhanced breast and ovarian cancer risk – either higher risk of an initial cancer (for unaffected women) or a recurrence or second primary cancer (for women already affected by cancer). Women with BRCA1 or BRCA2 mutations have approximately a 33% to 50% risk of developing breast cancer by age 50 (17;18). By age 70, a mutation carrier’s risk of developing breast cancer is 56% to 87% (18-20).

Other prevention strategies recognized by the National Cancer Institute include suppression of hormonal factors, reducing radiation exposure, dietary factors, and prophylactic mastectomy (21;22).

## **BREAST CANCER IN NEW JERSEY**

**Incidence.** The American Cancer Society estimates that, among women in the U.S., 203,500 cases of breast cancer will be newly diagnosed in 2002. In New Jersey alone, approximately 6,900 breast cancer cases will be diagnosed in 2002 (1).

The breast cancer incidence rates in New Jersey increased from 1979 to the early 1990s and have remained fairly stable since

that time\* (Figure 1). New Jersey females had similar incidence rates to U.S. females in 1999; 141.0 versus 139.1 per 100,000\*\*. However, incidence rates in white females were higher in New Jersey than in the U.S. in 1999; 146.6 versus 143.0 per 100,000\*\*. Incidence rates in black females in New Jersey were lower than in the U.S.; 111.7 versus 123.9 per 100,000\*\*. In a recent report published by the New Jersey State Cancer Registry, a lower proportion of Hispanic and black women were diagnosed in the earlier stages of breast cancer than were non-Hispanic women (23-25).

In New Jersey, the percent of breast cancers diagnosed in the early stage (in situ and localized) has steadily increased in both black and white women in the past ten years. However, the percent of white women being diagnosed in the early stages is higher than that for black women in New Jersey (68% versus 60%) in 2000\* (Figure 2).

**Mortality.** The American Cancer Society estimates that about 39,600 breast cancer deaths will occur among women in the U.S. in 2002 (1). Approximately 1,400 New Jersey women will die from breast cancer in 2002 (26). Consistent with 1999 U.S. mortality rates, black women in New Jersey have a higher mortality rate compared to white women, despite the incidence rates of black women being lower (Figure 1 & 3). In 1999, white females in New Jersey had a higher rate of breast cancer mortality than the U.S. (29.5 per 100,000\*\* versus 26.3 per 100,000\*\*). However, New Jersey has lower rates of breast cancer mortality in black females than in the U.S. (32.8 per 100,000\*\* versus 35.8 per 100,000\*\* (Figure 3). Breast cancer mortality in Hispanic females in New Jersey was only half of the mortality rate of non-Hispanic white and blacks (25;27).

In 1995, a Breast Cancer Summit was held to gather New Jersey physicians, researchers, health professionals, and organizations to address the serious healthcare crisis in breast cancer. In a report of the Breast Cancer Summit (28), *Breast Cancer Mortality in New Jersey: A Time for Action*, five areas for action were identified for New Jersey: early detection, therapeutics, research, healthcare policy, and data. Over half a decade later in 2002, the Breast Cancer Workgroup concurs that these remain important priorities for the state. Therefore, the Breast Cancer Workgroup has used the action plan of the Breast Cancer Summit as a basis for addressing breast cancer mortality in this report.

**Prevention and Early Detection.** Data from the Behavioral Risk Factor Surveillance System (BRFSS) indicate that the percent of New Jersey women receiving mammography increased greatly between 1991 and 2000. The number of women reporting that they never had a mammogram and a breast exam decreased in all age groups (Figure 4). This increase in screening rates occurred across all age groups. Despite positive trends in New Jersey mammography use, New Jersey rates remain below U.S. rates for breast cancer screening in women over age 50.

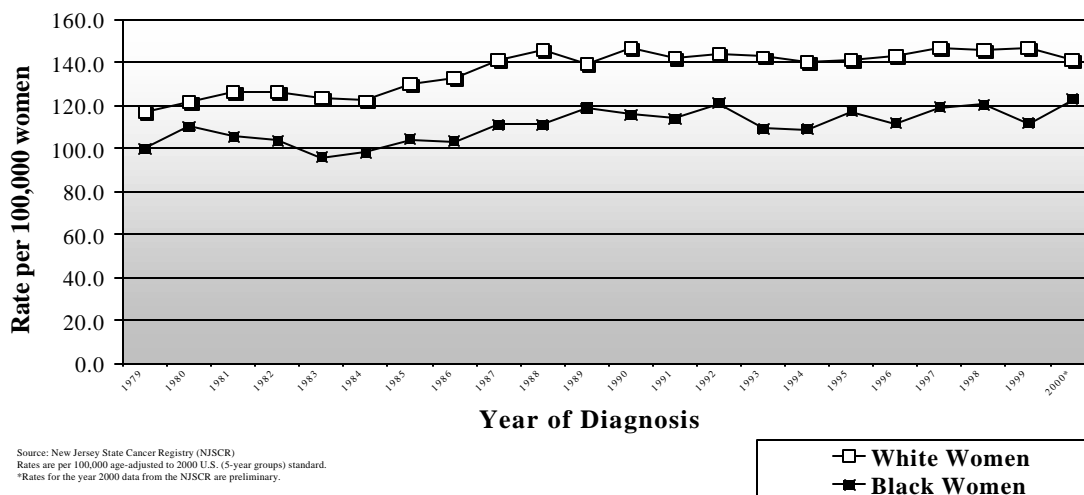
**Conclusion.** New Jersey data reveal that white women have the highest incidence of breast cancer in every age group. However, black women have a higher mortality from breast cancer, with major differences occurring at ages 45 to 64. These differences may result from the disparity observable by race in healthcare prevention and treatment services, which is reflective of access-to-care problems in New Jersey.

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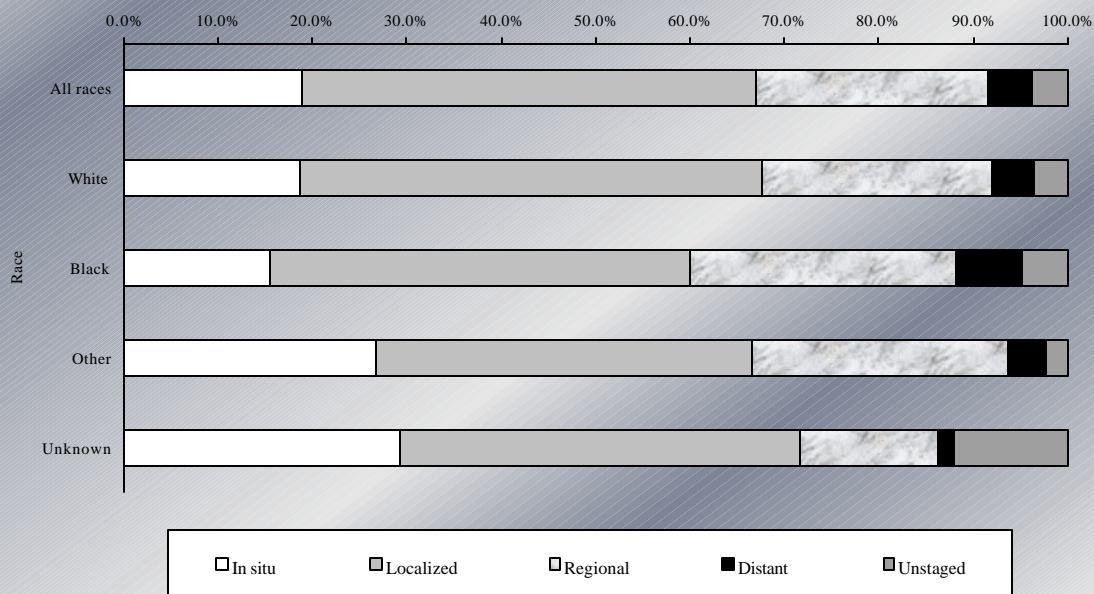
\*Incidence rates for the year 2000 data from the New Jersey State Cancer Registry are preliminary.

\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

**Figure 1: Invasive Breast Cancer Incidence Rates  
Among New Jersey Women, 1979-2000\***



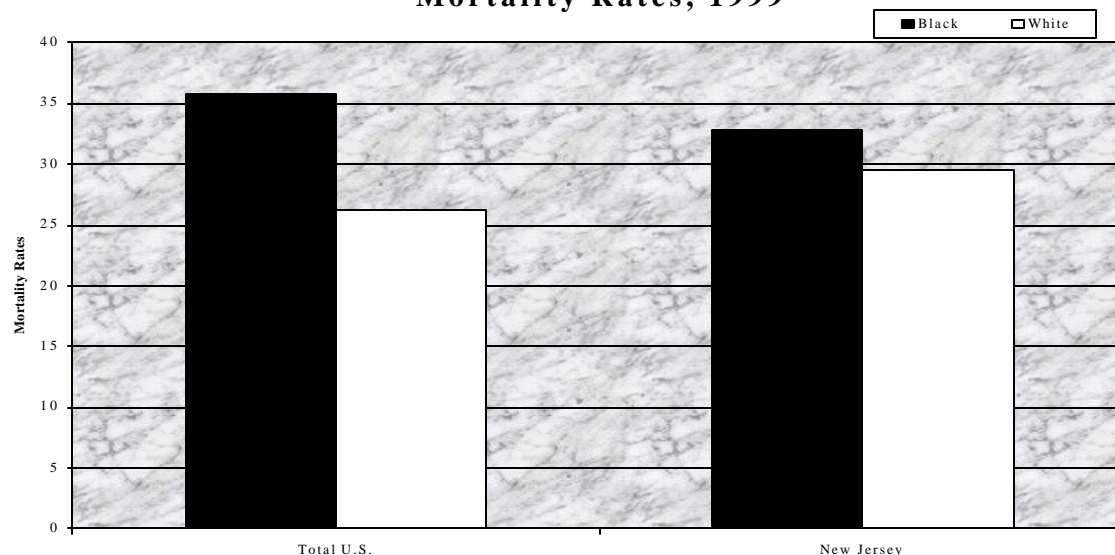
**Figure 2: Stage of Diagnosis for Female Breast Cancer in New  
Jersey by Race, 2000\***



Source: NJSCR; \*2000 data from the NJSCR are preliminary.

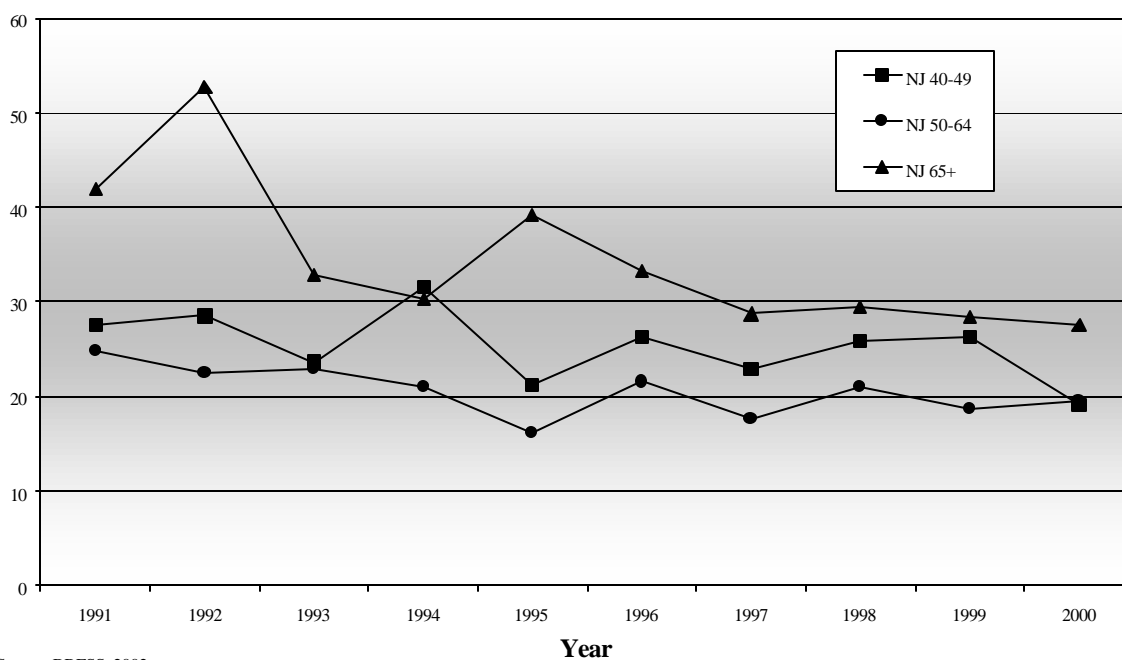


**Figure 3: U.S. and New Jersey Female Breast Cancer Mortality Rates, 1999**



Source: National Center for Health Statistics; Rates are per 100,000 and age-adjusted to the 2000 U.S. (5-year groups) standard.

**Figure 4: Female Respondents, age 40 and older, who report that they have never had a mammogram and a breast exam**



Source: BRFSS, 2002



Below are the Healthy New Jersey 2010 goals relating to breast cancer.

**Healthy New Jersey Goal 1: Increase the percentage of females aged 40 and over who received a clinical breast examination and a mammogram within the past two years, by 2010.**

**Table 1. Baseline data and projected target rates to reduce the death rate from female breast cancer.**

Populations	1997-1999 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total females 40+	65.0	75.0	+15.4	85.0	+30.8
White non-Hispanic females	66.2	75.0	+13.3	85.0	+28.4
Black non-Hispanic females	62.8 <sup>^</sup>	75.0	+19.4	85.0	+35.4
Asian/Pacific Islander	#	#	#	#	#
Hispanic females	56.7 <sup>^</sup>	75.0	+32.3	85.0	+49.9
Females 50-64	70.9	85.0	+19.9	90.0	+26.9
Females 65+	60.4	75.0	+24.2	85.0	+40.7
MCO records older enrolled females (1998-1999)	68.3	85.0	+24.5	90.0	+31.8

<sup>^</sup>Estimate has a relatively large standard of error or more than two percent.

<sup>#</sup>Data are statistically unreliable.

Source: Healthy New Jersey 2010

**Healthy New Jersey Goal 2: Increase the percentage of female breast cancers diagnosed in early (in situ/local) stage of disease, by 2010.**

**Table 2. Baseline data and projected target rates to increase the percentage of females who received a clinical breast examination and a mammogram within the past 2 years.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total	65.9	75.0	+13.8	85.0	+29.0
White	66.7	75.0	+12.4	85.0	+27.4
Black	58.5	75.0	+28.2	85.0	+45.3
Asian/Pacific Islander	#	#	#	#	#
Hispanic <sup>‡</sup>	69.0	75.0	+8.7	85.0	+23.2
Females 65+	64.6	75.0	+16.1	85.0	+31.6

<sup>‡</sup>1998 Hispanic data unavailable, using 1996 data.

<sup>#</sup>Data are statistically unreliable.

Source: Healthy New Jersey 2010

**Healthy New Jersey Goal 3: Reduce the age-adjusted death rate from female breast cancer, by 2010.**

**Table 3. Baseline data and projected target rates to increase the percentage of female breast cancers being diagnosed in early stages.**

<b>Populations</b>	<b>1998 Baseline Data</b>	<b>Target</b>	<b>Percent Change</b>	<b>Preferred 2010 Endpoint</b>	<b>Percent Change</b>
Total age-adjusted	24.7	17.0	-31.2	17.0	-31.2
White age-adjusted	24.7	17.0	-31.2	17.0	-31.2
Black age-adjusted	28.1	23.3	-17.1	17.0	-39.5
Asian/Pacific Islander age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#
Females 50-64	56.2	47.3	-15.8	20.0	-64.4
Females 65+	143.7	120.0	-16.5	103.0	-28.3

<sup>#</sup>Data are statistically unreliable.  
Source: Healthy New Jersey 2010

In support of the Healthy New Jersey 2010 goals for breast cancer, the recommendations of the Breast Cancer Workgroup are summarized below for the following three topic areas in priority order:

- Awareness and Education
- Research and Surveillance
- Treatment

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## GOALS, OBJECTIVES AND STRATEGIES

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### **AWARENESS AND EDUCATION FOR BREAST CANCER**

To increase screening for breast cancer, increase early diagnosis, and decrease death rates, the Breast Cancer Workgroup identified education as a priority for New Jersey. The education process has four components: (1) developing a consensus message, (2) educating the public, (3) educating patients, and (4) educating healthcare professionals. An effective message will be one that encompasses all aspects of breast health and is adopted by professionals, communities, grassroots organizations, and advocacy groups through collaboration and partnerships. Although the Breast Cancer Workgroup discussed the importance of educating all New Jerseyans about breast health and quality breast cancer care, high-risk populations must be targeted first in order to address disparities apparent in the incidence and mortality data. Please see the Research component of this chapter for more information about identification of high-risk populations for breast cancer.

**Building Consensus.** The process of education must begin with achieving consensus on approaches to breast cancer prevention, early detection, and treatment. Currently, several different messages are being disseminated about breast cancer screening, for example. Most organizations recommend annual mammograms for women ages 40 and older based on strong evidence that mortality is reduced (7;8;10;29). However, recommendations for breast self-examination and clinical breast examination vary drastically. The U.S. Preventive Services Task Force concludes that the evidence is insufficient to recommend for or against teaching or performing routine breast

self-examination and that the evidence is insufficient to recommend for or against routine clinical breast examination alone to screen for breast cancer (10). Conversely, the American College of Radiology recommends that BSEs be performed monthly and that CBEs be performed annually (7). Without a consensus message, breast cancer education is inconsistent and sporadic, and awareness about the importance of prevention and early detection is not universal.

#### **Awareness and Education for the Public.**

Data from the New Jersey State Cancer Registry (presented earlier in this chapter) demonstrates that some segments of the New Jersey population are suffering disproportionately from breast cancer. Although white New Jerseyans have higher incidence of breast cancer, more black women are dying from it. Focused efforts by private sector organizations and federal and state governments to educate women about the importance of breast cancer prevention and early detection and to provide opportunities for mammography screening have resulted in dramatic increases in mammography screening rates over the past two decades. However, according to data from BRFSS, women in New Jersey are not utilizing breast cancer screening effectively. In 2000, more New Jersey women than the U.S. median (47.0 versus 32.9) reported never having had a mammogram or clinical breast exam (Figure 4). According to the Peer Review Organization of New Jersey, approximately 50% of women with Medicare eligible to receive a mammogram do not take advantage of this Medicare-covered service.

Many studies have been conducted to identify both barriers to screening and interventions needed to overcome barriers, such as

cost (30), lack of knowledge regarding screening (31), physician recommendation (32), language (33), cultural sensitivity issues (33), inaccessible screening sites and transportation (33). In a recent New Jersey study, participants revealed that they are not motivated to obtain screening services because “prevention is not a priority” (33). (See the Access and Resources Chapter for additional information on this study.)

Efforts to educate women about the need for breast cancer screening have varied in their ability to overcome barriers and increase screening rates. Some successful attempts to persuade women of the necessity of screening mammograms have used nurse practitioners, videotapes, in-person counseling delivered by nurses or peers, mailings, and telephone counseling (34-39). Some have used social networks (40;41), community or healthcare systems approaches (42;43) rather than focusing exclusively on individual behavior change.

Teaching breast self-care as breast changes occur in the adolescent girl can influence positive behaviors such as performing breast self-examinations and seeking regular professional breast examinations. Health promotion behaviors are often taught in high school, but little research has been conducted on teaching breast health in a high school setting, particularly breast cancer early detection and screening (44). Another study found that educational lessons could improve knowledge and attitudes of adolescent girls with respect to breast self-examination (45).

Interventions should focus not only on improving one-time screening but also on improving repeat adherence. Recent research found that “off-schedule” women (women screened at least once and non-adherent with recommended screening intervals) had greater knowledge and were more positive about

mammography than women who had never been screened, but their measures on these indicators were lower than those for “on-schedule” women (46). Brief interventions from healthcare providers emphasizing the importance of repeat screening should be delivered to “off-schedule” women.

Given both the importance and the complexity of the issues, women should have access to the best possible relevant information regarding both benefits and risks of screening, presented in an understandable and usable form. In addition, educational information to accompany this risk-benefit information should be prepared to lead women step by step through a process of informed decision-making (9). The Breast Cancer Workgroup also proposes that breast cancer screening and early detection be taught early to foster knowledge about lifelong breast health.

#### **Awareness and Education for the Cancer Patient.**

Not only is it essential that awareness be increased in the general public, awareness must also be increased in the patient population. For a number of reasons, follow-up for evaluation and treatment is often not completed. In a study of 10,434 mammograms conducted between 1995 and 1997, 44% of women with abnormal mammograms had no further follow-up (47). Lack of understanding by the patient about the next steps often contributes to incomplete follow-up, as does inconsistent sharing of information (20). Women also report that lack of communication that follow-up was necessary, cost of lost wages and medical care, system factors, and fear represent barriers to appropriate follow-up (48).

Primary care physicians hold a strategic position for the delivery of preventive care services because of their access to the patient population and their long-term relationship with patients. It has been shown that by

implementing a multi-faceted intervention, patients are more likely to assume an active role in decision-making (49). Also, pre-consultation education appears to be an effective clinical strategy for helping patients gain an accurate understanding of treatment options before meeting with their physicians (50). This information must be presented in an understandable and culturally appropriate format.

**Awareness and Education for Healthcare Practitioners.** More than 20% of New Jersey women reported no mammogram within the past two years, for ages 40 to 64. Data from BRFSS 2000 indicate that, for women over 65, nearly 26% reported no mammogram within the past two years, which is slightly higher than the U.S. average percentage of 23%. These numbers must be improved to effectively decrease mortality and increase early detection of breast cancer.

As noted earlier, primary care physicians are in a strategic position to influence preventive care services. A review focusing on breast

cancer screening concluded that several interventions, notably reminders and audit and feedback, can increase physician use of mammography (49). Tailored interventions, using a package that addresses specific professional barriers to change in a particular setting, are recommended to improve delivery of preventive services in primary care. Additionally, research has shown that physicians can be assisted in their delivery of preventive services through group education, reminder devices, and changes to the organization of care (49).

The Breast Cancer Workgroup recommends that healthcare professionals encourage their female patients to use available screening methods for breast cancer. Given the observed variation among populations and different barriers for each population, interventions must be tailored. Below we present the Breast Cancer Workgroup's recommendations for a multidimensional approach to addressing breast cancer education in New Jersey.

#### **GOAL BR-1:**

**To improve public understanding of breast health, breast cancer, and screening to promote the value of early detection.**

##### **Objective BR-1.1:**

To build consensus on what the public message should be regarding breast cancer education, impact of certain health and lifestyle factors, screening and treatment, and the benefits and risks of early detection.

**Strategies:**

- (BR-1.1.1) Convene a diverse group of breast cancer experts, advocates, and consumers at state and community levels.
- (BR-1.1.2) Review and summarize the most current scientific literature about breast cancer screening, early detection, and treatment.
- (BR-1.1.3) Develop an overall breast cancer message for the general public, as well as targeted culturally appropriate messages for high-risk, underserved, and special populations based on research findings. (See also Goal BR-7: Research and Surveillance.)
- (BR-1.1.4) Establish priorities to most effectively reach the targeted population with breast cancer information.

**Objective BR-1.2:**

To develop and implement a statewide breast cancer public awareness campaign to increase utilization of breast cancer screening services (in accordance with accepted public health practice and recommendations of the Centers for Disease Control and Prevention).

**Strategies:**

- (BR-1.2.1.) Develop media campaigns specifically promoting the availability of no-cost breast cancer screenings for those eligible through the New Jersey Cancer Education and Early Detection (NJCEED) Program. Develop media campaigns specifically promoting the Medicaid Breast and Cervical Cancer Treatment Program for eligible women that are screened and/or diagnosed through NJCEED.
- (BR-1.2.2) Collaborate with organizations and entities to communicate messages and effectuate the breast cancer campaign, including (but not limited to): the New Jersey Primary Care Association, American Cancer Society, Breast Cancer Resource Center/YWCA Princeton, Susan G. Komen Breast Cancer Foundation, Medical Society of New Jersey, New Jersey Association of Osteopathic Physicians and Surgeons, New Jersey Hospital Association, New Jersey State Commission on Cancer Research, Cancer Institute of New Jersey, Health Research and Educational Trust of New Jersey, and Peer Review Organization of New Jersey, Inc.
- (BR-1.2.3) Provide public service announcements and media information on breast cancer in English, Spanish, and other languages as needed.

- (BR-1.2.4) Provide training for multi-level, multi-lingual, multi-cultural Speaker's Bureau to implement community breast cancer education and screening activities.
- (BR-1.2.5) Distribute promotional incentives to encourage women to undergo mammography and become educated about breast cancer by offering free or discounted items from local retailers.
- (BR-1.2.6) Establish and publicize a central toll-free telephone number in the New Jersey Department of Health and Senior Services that will act as a clearinghouse for *all New Jersey cancer information* (e.g., programs, services, support groups, etc.). Breast cancer screening services, especially sites with free and reduced-charge screening for low-income and uninsured women, will be emphasized.

### Objective BR-1.3:

To develop and disseminate breast cancer educational materials and resources to increase knowledge, improve public understanding of the value of screening and early detection, and promote high-quality breast health, paying special attention to vulnerable, high-risk populations.

### Strategies:

- (BR-1.3.1) Identify existing, and develop as needed, breast cancer *educational materials* to use in reaching all women, especially those at highest risk. Disseminate materials appropriately.
- (BR-1.3.2) Identify existing, and develop as needed, *educational programs*, and projects to promote breast cancer early detection and assist all women, especially those at highest risk.
- (BR-1.3.3) Identify existing, and develop as needed, breast cancer educational materials that are translated into multiple languages as appropriate, including Spanish, Arabic, Polish, Russian, Chinese, and other Asian languages.
- (BR-1.3.4) Provide comprehensive breast cancer educational materials to appropriate local and statewide community organizations for distribution to their constituencies.
- (BR-1.3.5) Recommend that organizations seek out professionals from various ethnic communities to provide breast cancer education and outreach in order that individuals can relate to their trainers.
- (BR-1.3.6) Disseminate breast cancer educational materials to high-risk groups through appropriate community members who care for them (e.g., healthcare providers, laypersons, and survivors).



- (BR-1.3.7) Distribute information about NJCEED sites to provide greater access to quality, no-cost breast cancer diagnostic and treatment services for uninsured women in the community.
- (BR-1.3.8) Expand culturally sensitive education and outreach programs for low-income, underserved communities who do not meet the NJCEED criteria.
- (BR-1.3.9) Provide cultural competency training to the individuals interfacing with the community (especially minority communities) for breast cancer awareness and education.
- (BR-1.3.10) Provide “faith-based” breast health and breast cancer education through a train-the-trainer program for church leaders in the black and Latino communities to provide ongoing breast health and breast cancer education, screening, and support resources for all women in their community, especially high-risk women.

**Objective BR-1.4:**

To increase education of high school students on breast cancer prevention and early detection by developing a curriculum on the life-saving value of good breast health habits.

**Strategies:**

- (BR-1.4.1) Develop a formal breast health high school curriculum in New Jersey in response to New Jersey state promotion of teaching BSE (breast self-examination).
- (BR-1.4.2) Work with the New Jersey Department of Education and advocate for full implementation of this breast health curriculum in all New Jersey high schools.
- (BR-1.4.3) Develop thoughtful, age-appropriate educational materials for teen-age students to teach breast health at an early age, including multi-media presentations, supporting posters, and brochures.
- (BR-1.4.4) Widely distribute high school focused breast educational materials for either assembly or classroom venues.
- (BR-1.4.5) Identify a method(s) to track the impact of teaching young women about breast health and breast cancer on later adherence to screening recommendations.

**GOAL BR-2:**

**To improve patient/client awareness and education about the importance of breast cancer rescreening and follow-up visits to maximize optimal outcomes.**

**Objective BR-2.1:**

To educate women who come in for breast cancer screening about early detection and the need to return for appropriate rescreening or diagnostic testing.

**Strategies:**

- (BR-2.1.1) Identify existing, and develop as needed, culturally appropriate materials that describe the importance of rescreening and follow-up visits, where necessary, and highlighting the importance of using a mammography facility that is FDA accredited. Distribute this information widely.
- (BR-2.1.2) Identify existing, and develop as needed, information for dissemination to community groups and advocacy groups about nationally recognized screening guidelines, where to go for screening, and the availability of programs for clients without health insurance, and to dispel fears and myths that exist around breast cancer.

**Objective BR-2.2:**

To increase appropriate treatment and follow-up for women who receive abnormal mammograms and/or abnormal clinical breast exams.

**Strategies:**

- (BR-2.2.1) Identify existing, and develop as needed, culturally appropriate materials to educate clients who receive abnormal screening results about the importance of appropriate and timely follow-up, treatment options available if they have been diagnosed with breast cancer, especially clinical trials.
- (BR-2.2.2) Identify existing, and develop as needed, culturally appropriate education materials for those clients who have completed breast cancer treatment about the importance of follow-up care, especially about the risk of lymphedema and the importance of early lymphedema management. Distribute information widely.

- (BR-2.2.3) Improve existing, and develop as needed, resource guides for breast cancer including treatment centers that participate in clinical research, available support groups, and where financial assistance can be obtained. Make the resource guide readily available by using websites, a central hotline, and wide distribution to healthcare professionals, public libraries, and grassroots and community agencies that have contact with women.

### **GOAL BR-3:**

**To improve the knowledge of healthcare practitioners about the importance of having an active provider role, assessing patients' risks of developing breast cancer, formulating a prevention plan based on that risk and encouraging more referrals.**

#### **Objective BR-3.1:**

To increase professional education on symptoms, risk factors, screening, risk reduction, and follow-up care for breast cancer.

#### **Strategies:**

- (BR-3.1.1) Create a curriculum with continuing education credits to provide information to healthcare practitioners on the following: (1) screening guidelines, (2) risk reduction, (3) symptoms of breast cancer and follow-up care, (4) genetic risk factor assessment, and (5) cultural competency. This curriculum should be interactive and developed in different formats and media, e.g., internet, audiotape, CDs, etc. by partnering with professional organizations.
- (BR-3.1.2) Widely distribute and promote this breast cancer curriculum through the Medical Society of New Jersey, the Academy of Medicine, and other professional and specialty groups.

#### **Objective BR-3.2:**

To measure and then increase the number of primary care providers who recommend mammography to appropriate patients.

**Strategies:**

- (BR-3.2.1) Educate primary care providers regarding which patients are appropriate for mammograms, focusing on those serving ethnically diverse and minority communities.
- (BR-3.2.2) Provide primary care providers with a current list of mammogram providers.
- (BR-3.2.3) Encourage primary care providers to increase referrals and improve patient awareness about breast cancer early detection and screening measures.

## RESEARCH AND SURVEILLANCE FOR BREAST CANCER

Earlier in this chapter the risk factors for breast cancer and disparities surrounding breast cancer care were identified. While the overall picture of breast cancer among New Jersey women is encouraging, there is need for improvement among specific subgroups of women. Statistics from the New Jersey State Cancer Registry demonstrate that between 1986 and 1995 the percentage of breast cancer cases diagnosed in the early stages (in situ and localized) varied by county of residence (4). Additionally, age-adjusted mortality rates for the years 1986-1995 varied among the 21 counties in New Jersey (4). The disparities in mortality rates by state likely depend on stage of disease at diagnosis, socioeconomic status, access to care, and adequacy of medical care (51). Although this information is well documented in the literature, New Jersey lacks a comprehensive needs and capacity assessment for breast cancer to identify populations in greatest need and their healthcare barriers.

It is a well-recognized fact that the incidence of breast cancer is generally higher for white than black women, with population-based data showing an approximately 20% higher rate for white women (52). However, there is a reverse trend among women less than 40 years old (52). Among older women (40 to

54 years), most of the difference between whites and blacks can be attributed to varying prevalences and effects of well-recognized reproductive and menstrual factors. However, among younger women (20 to 39 years), the ethnic differences are less well understood (52).

In 1999, the Susan G. Komen Breast Cancer Foundation, North Jersey Affiliate, completed an updated community needs assessment (53) for the nine northern counties in New Jersey. The Breast Cancer Resource Center/Princeton YWCA completed a community needs assessment in Central New Jersey (54). Population maps, breast cancer incidence and mortality graphs, and provider inventory maps were created to identify unmet needs in the areas of prevention, early detection, and treatment for breast cancer. A study of this nature must be kept current for all of the counties in New Jersey to effectively identify the unmet needs for breast cancer.

The Cancer Epidemiology Services, New Jersey Department of Health and Senior Services, used their geographic information system (GIS), spatial statistical software, and cases of women diagnosed 1995-1997 with breast cancer (n=20,703) to identify geographic areas in New Jersey with high proportions of distant-stage breast cancer (55). Two areas in northeastern New Jersey were identified, with relatively high

proportions of black or Hispanic women and of linguistically isolated households in the population. Virtually all the women with breast cancer in these two areas were within two miles of a mammography facility. Similar analyses conducted on a periodic basis are needed to continue to identify areas in need of breast cancer education and screening services and to evaluate the effect of provision of these services, including income level and insurance status.

Although some data have been compiled stratifying for each type of cancer the incidence, prevalence, treatment access, mortality, etc. by age, race, gender, and geographic location, these data are largely incomplete (55). Existing data do not permit all factors to be simultaneously assessed, and summary measures frequently hide vast

disparities within subgroups, which may be amenable to intervention and improvement. Needed are studies to develop a more comprehensive database, as well as analytic work targeting those subgroups offering the greatest chances for improvements. Such efforts will help guide the cost-effective deployment of targeted resources toward those areas in need. Also needed are studies that help define innovative ways to overcome current barriers. Statistics reported on health indicators should be stratified by a variety of factors. Among women, for example, all age groups do not benefit equally from mammography screening. Furthermore, population access apparently differs dramatically in different parts of the state. Detailed data are required to identify those in greatest need of services. Resources are necessary to then provide those services.

#### **GOAL BR-4:**

**To adequately identify and address areas and populations at higher than expected risk of breast cancer incidence and mortality in New Jersey in order to learn where education and awareness efforts are most needed.**

#### **Objective BR-4.1:**

To identify areas in New Jersey where breast cancer mortality risk is greatest.

#### **Strategies:**

- (BR-4.1.1) Update existing maps and develop new maps, tables, etc. that identify and describe geographic areas and population groups at high risk of breast cancer mortality, using demographic, service utilization, and epidemiologic data.

- (BR-4.1.2) Assess consumer-related barriers to breast cancer screening (cultural barriers, help-seeking behaviors, socioeconomic factors, transportation, etc.), provider-related barriers (accessibility, waiting time, capacity, communication, etc.), institution-related barriers, and system-level barriers (analysis of payer data, claims data, policies and regulations, and standards of care).

#### **Objective BR-4.2:**

To monitor and evaluate new and existing strategies that are developed and implemented for breast cancer early detection and treatment in high-risk populations with regard to the barriers identified in BR-4.1.2.

#### **Strategies:**

- (BR-4.2.1) Conduct a cost analysis to determine the cost-effectiveness of educational programs and interventions to increase breast cancer screening in higher risk populations in New Jersey.
- (BR-4.2.2) After implementation of a strategy to promote breast cancer screening in a higher risk group, evaluate the success of the strategy.
- (BR-4.2.3) Partner with groups developing breast cancer education and awareness programs in order to build in continuous quality improvement mechanisms during the planning stages of educational programs and interventions, especially evaluation plans.

## **TREATMENT FOR BREAST CANCER**

Many treatment options are available for women diagnosed with breast cancer. However, many women find it difficult to make decisions about treatment. Clinical trials are the major avenue for discovering, developing, and evaluating new therapies. However, only about 3% of all adult cancer patients participate in clinical trials. It is important to increase physician and patient awareness of, and participation in, clinical trials if we are to test new treatments more rapidly, find more effective treatments, and broaden the options available to patients (3).

Several New Jersey organizations provide current information about breast cancer treatment. Currently, the Commission on Cancer Research produces a publication that describes cancer resources available in New Jersey. Websites, such as [emerging-med.com](http://emerging-med.com), provide resources to match individuals to clinical trials worldwide. State programs, such as NJCEED, provide treatment for eligible women who are diagnosed through the NJCEED program (Appendix E). However, all of these resources are not coordinated to provide comprehensive information about breast cancer resources available in New Jersey.

A new NCI initiative, the Cancer Care Outcomes Research and Surveillance Consortium, will provide more detailed information on how to link measures of quality care to outcomes important to patients as we develop systems for evaluating quality of care. Similar studies are being supported by major professional organizations as well as by NCI (3). A report from the Institute of Medicine suggests that future research is needed to eliminate breast cancer mortality, as screening mammography does not detect all cancers (56).

The Breast Cancer Workgroup realizes that much additional work can be done to improve treatment techniques for breast cancer in New Jersey. However, the group determined that the first priority is to increase awareness and access to state-of-the-art treatment. As

research and development progresses at a rapid pace, so must a parallel system to assure that individuals are aware of the treatment options that exist and can access state-of-the-art treatment readily. After all, without awareness and access, even the most beneficial interventions will not be effective.

The Breast Cancer Workgroup recommends that improving breast cancer treatment should begin by increasing awareness of state-of-the-art treatment. Continuing medical education should be offered to physicians, and a centralized clearinghouse of breast cancer information should be available for the public. Additionally, the Breast Cancer Workgroup recognizes the importance of clinical trial enrollment for state-of-the-art breast cancer treatment.

#### **GOAL BR-5:**

**To ensure that all New Jersey residents diagnosed with breast cancer receive state-of-the-art cancer treatment and services, taking into consideration all variables (including age, stage of tumor, residence, and socioeconomic status), including clinical trials that comply with nationally recognized guidelines**

#### **Objective BR-5.1:**

To enroll all interested and eligible patients in evidence-based, currently approved clinical research trials for breast cancer and provide similar treatment options for those not interested or eligible.

#### **Strategies:**

- (BR-5.1.1) Provide healthcare professionals with information about how to screen all patients diagnosed with breast cancer in New Jersey for their eligibility for currently approved clinical research trials.



- (BR-5.1.2) Educate healthcare professionals about the need to use evidence-based, currently recognized community standards of care for those breast cancer patients not eligible for clinical research trials, or those patients not choosing to be a part of a clinical research trial, or those patients who do not have clinical research trial availability. This can be done through continuing medical education programs partnering with professional organizations.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

Breast Cancer Resource Center / YWCA Princeton: BR-1.1.3, BR-1.2.2, BR-1.2.3, BR-1.2.4, BR-1.2.5, BR-1.2.6, BR-1.3.2, BR-1.3.4, BR-1.3.6, BR-1.3.7, BR-1.4.4, BR-2.1.1, BR-2.1.2, BR-2.2.1, BR-2.2.2, BR-3.2.3

New Jersey Department of Health and Senior Services: BR-1.2.2; BR-1.2.3; BR-1.2.6; BR-2.1.9; R-2.1.10; BR-3.1.1; BR-3.2.2; BR-4.1.1; BR-4.2.1; BR-4.2.1; BR-4.2.2; BR-4.2.3

New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection (NJCEED): BR-1.1.1; BR-1.1.2; BR-1.1.3; BR-1.1.4; BR-1.2.1; BR-1.2.2; BR-1.2.6; BR-1.3.1; BR-1.3.2; BR-1.3.3; BR-1.3.4; BR-1.3.5; BR-1.3.6; BR-1.3.7; BR-1.3.9; BR-1.3.10; BR-2.1.1; BR-2.1.2; BR-3.1.1; BR-3.1.2; BR-3.2.1; BR-3.2.2; BR-3.2.3; BR-4.1.2; BR-4.2.1; BR-4.2.2; BR-4.2.3

New Jersey Hospital Association: BR-1.3.7; BR-2.2.3; BR-3.2.2; BR-3.2.3

Komen NJ Race for the Cure: BR-1.2.3, BR-1.2.4, BR-1.2.5, BR-1.3.1, BR-1.3.3, BR-1.3.4, BR-1.3.5, BR-1.3.6, BR-1.3.8, BR-1.3.9, BR-1.3.10, BR-1.4.2, BR-1.4.4, BR-2.1.1, BR-2.1.2, BR-2.2.1, BR-2.2.2, BR-2.2.3, BR-4.1.1, BR-4.1.2, BR-4.2.3

Susan G. Komen Breast Cancer Foundation, North Jersey Affiliate: BR-1.1.1; BR-1.1.2; BR-1.1.3; BR-1.1.4; BR-1.2.1; BR-1.2.2; BR-1.2.3; BR-1.2.4; BR-1.2.5; BR-1.2.6; BR-1.3.1; BR-1.3.2; BR-1.3.3; BR-1.3.4; BR-1.3.5; BR-1.3.6; BR-1.3.7; BR-1.3.8; BR-1.3.9; BR-1.3.10; BR-1.4.1; BR-1.4.2; BR-1.4.3; BR-1.4.4; BR-1.4.5; BR-2.1.1; BR-2.1.2

## BREAST

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Improve public understanding	1.1: Build consensus on public message	BR-1.1.1						
		BR-1.1.1						
		BR-1.1.1						
		BR-1.1.4						
	1.2: Develop/implement statewide public awareness campaign	BR-1.2.1						
		BR-1.2.2						
		BR-1.2.3						
		BR-1.2.4						
		BR-1.2.5						
		BR-1.2.6						
	1.3: Develop/disseminate educational materials and resources	BR-1.3.1						
		BR-1.3.2.						
		BR-1.3.3						
		BR-1.3.4						
		BR-1.3.5						
		BR-1.3.6						
		BR-1.3.7						
		BR-1.3.8						
		BR-1.3.9						
		BR-1.3.10						
	1.4: Increase education of high school students	BR-1.4.1						
		BR-1.4.2						
		BR-1.4.3						
		BR-1.4.4						
		BR-1.4.5						
2: Patient awareness and education regarding rescreening and follow-up	2.1: Educate women regarding appropriate re-screening or diagnostic testing	BR-2.1.1						
		BR-2.1.2						
	2.2: Increase treatment and follow-up for those with abnormal mammograms or clinical breast exams	BR-2.2.1						
		BR-2.2.2						
		BR-2.2.3						
3: Improve healthcare practitioners' knowledge	3.1: Increase professional education	BR-3.1.1						
		BR-3.1.2						
	3.2: Measure/increase healthcare provider referral	BR-3.1.1						
		BR-3.1.2						
		BR-3.1.3						

Target Completion Date

## BREAST

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
4: Identify/address high-risk incidence and mortality	4.1: Identify high-risk areas	BR-4.1.1						
		BR-4.1.2						
	4.2: Monitor/evaluate strategies for high-risk populations	BR-4.2.1						
		BR-4.2.2						
		BR-4.2.3						
5: Ensure state-of-the-art treatment for all New Jersey residents	5.1: Enroll interested and eligible patients in clinical research trials	BR-5.1.1						
		BR-5.1.2						

Target Completion Date

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## CHAPTER 7. Cervical Cancer

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## CERVICAL CANCER

### IMPORTANCE OF CERVICAL CANCER FOR CANCER PREVENTION AND CONTROL

Cervical cancer is a highly preventable and curable disease. Most cervical cancers develop over a relatively long period of time, allowing for early detection and treatment (1;2). The Papanicolaou smear, developed by George Papanicolaou and implemented for widespread screening in the 1940s (3), is the most common test used to screen for cervical cancer, and is widely available, and is covered by most insurance plans and government programs. Cervical cancer incidence and mortality rates have declined considerably (Figure 1), and screening rates have increased in the United States over time. Despite the tremendous progress made with cervical cancer, it is estimated that 13,000 U.S. women will be diagnosed with cervical cancer and 4,100 will die from this disease in 2002 .

Deaths from cervical cancer began falling dramatically, beginning in 1970 with the development of screening programs utilizing the Pap test to detect cervical cancer in its early, most treatable stages (3). However, due to lack of regular screening or inadequate follow-up and treatment of precancerous changes found during routine screening, not all populations have experienced a reduction in mortality (5). In the absence of screening, a 20-year-old average-risk woman has approximately a 250 in 10,000 chance of developing invasive cervical cancer during the rest of her life and approximately a 118 in 10,000 chance of dying from it (3). In addition, rates for carcinoma in situ peak between the ages of 20 and 30 (6). The lead-time from the development of precancerous lesions to invasive cancer is estimated at 8 to 9 years (6). During this process, abnormal tissue can easily be detected by a Pap smear and then removed by a clinician (7). Most of

the cervical cancer deaths occur in women who have never had a Pap test, and some occur in women who recently received negative test results (8). Nearly one-half of all U.S. women with invasive cervical cancer are diagnosed at a late stage (9). Case control studies clearly demonstrate that women with invasive cervical cancer were less likely to have been screened compared to controls (3;10), and decreased mortality and incidence of invasive cervical cancer have been described in populations following implementation of Pap screening (6). Compared to other cancers, cervical cancer is not a leading cause of mortality; however, it remains a priority and important issue because it is nearly 100% preventable with early detection.

Women at risk for developing cervical cancer are those who are or who ever have been sexually active (6;10); are not being screened on a routine basis (6;11) had an early onset of sexual intercourse (6;12) have a history of multiple partners (6;12); have a history of sexually transmitted disease (6), especially HPV (2;13;14) and HIV (15); suffer from obesity (16); and/or smoke (6;17;18). Research has shown that women from minority groups, especially populations of color, are at particular risk for the disease, as are women for whom access to routine healthcare services is at best a challenge and at worst non-existent (7). It is generally agreed that the most important risk factor for cervical cancer is infection by Human Papilloma Virus (HPV). In fact, HPV DNA is present in 93% of cases involving cervical cancer and its precursor lesions. Although there is currently no cure for HPV infection, providers can treat the warts and abnormal cell growth caused by these viruses and prevent them from developing into cancer. However, given the availability of early detection and treatment procedures for cervical cancer, major risk factors for death

are lack of appropriate screening and lack of prompt follow-up for abnormalities (19-21).

Screening with HPV plus Pap tests every two years appears to save additional years of life at reasonable costs compared with Pap testing alone (incremental cost: \$76,183 / Quality Adjusted Life Year [QALY] (21). Another study found that AutoPap, a new cervical cancer screening technology, increased survival at the lowest cost, estimating that cost per year of life saved rose from \$7,777 with quadrennial screening to \$166,000 with annual screening (22).

In October 2000, the federal government passed the Breast and Cervical Cancer Prevention and Treatment Act of 2000. It was adopted in New Jersey as of July 1, 2001. Under provisions of this Act, women who are qualified and screened through the New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection Programs (NJCEED), with federal or state funds, and who are diagnosed with breast or cervical cancer, are eligible for treatment under Medicaid. (See Appendix E for further information on NJCEED.)

Although Pap smear screening remains the best available method of reducing the incidence and mortality of invasive cervical cancer (2), screening programs have not yet eradicated this cancer completely in any population (5). Despite the recognized benefits of Pap smear screening, substantial subgroups of American women have not been screened or are not screened at regular intervals (2). Reasons offered for failure to eradicate the disease have focused on either lack of regular screening or inadequate follow-up and treatment of precancerous changes found during routine screening (1;7). Clearly needed are a better understanding of and increased attention to the reasons why

women are not utilizing this screening procedure more effectively.

## **CERVICAL CANCER IN NEW JERSEY**

**Incidence.** The American Cancer Society estimates that, in 2002, there will be 400 new cervical cancer cases in New Jersey (1). Since 1979 incidence rates for invasive cervical cancer have been decreasing in the U.S. and New Jersey. While the cervical cancer incidence rate (all races combined) in New Jersey has declined from 14.4 per 100,000\*\* women in 1979 to 10.0 per 100,000\*\* women in 2000\*, population subgroups have experienced substantially different rates (23) (Figure 1). Despite the decline in incidence rates, black women in New Jersey still had approximately twice the rate of white women (17.0 versus 8.9 per 100,000\*\*) in 2000\* (23) (Figure 1).

Of the 10.0 per 100,000\*\* new cases of invasive cervical cancer diagnosed in 2000\*, more than one-quarter (27.5%) were diagnosed at the regional stage, a stage at which these women statistically have only a 49% chance of surviving five years (19). In addition, 7.1% of new cervical cancer diagnoses are at the distant metastasis stage, a stage at which women statistically have only a 9% chance of surviving for five years (19) (Figure 2).

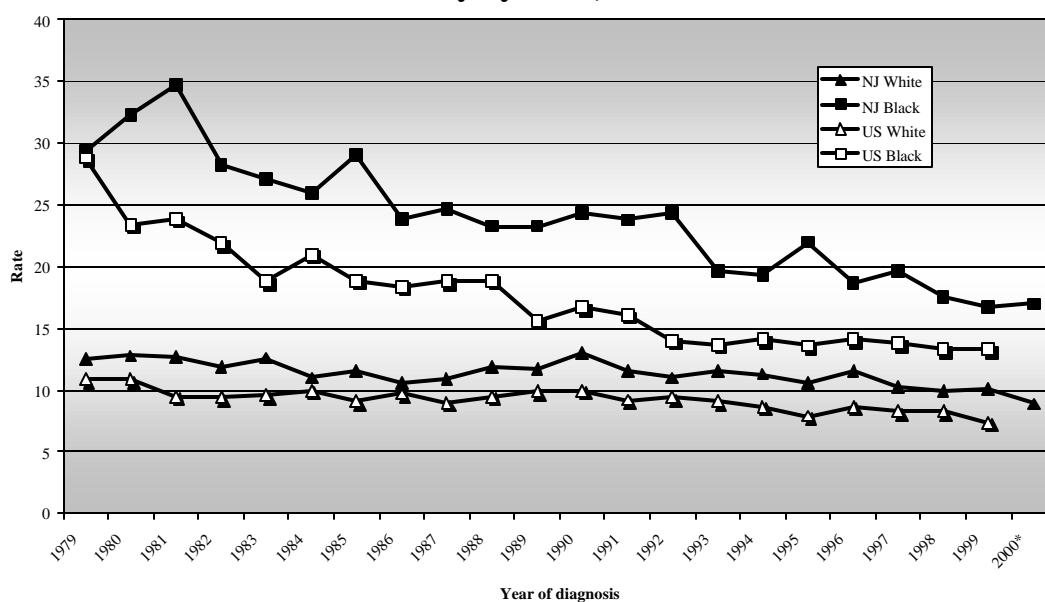
Trend data are not currently available for Hispanic women. However, a recent report from the New Jersey State Cancer Registry found that for the period 1990-1996, Hispanic women had a cervical cancer rate of 16.7 per 100,000 compared to 8.8 among white women and 15.6 among black women. Data from other states and the U.S. as a whole show similar cervical cancer rates among Hispanic and black women (24).

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\*Incidence rates for the year 2000 data from the New Jersey State Cancer Registry are preliminary.

\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

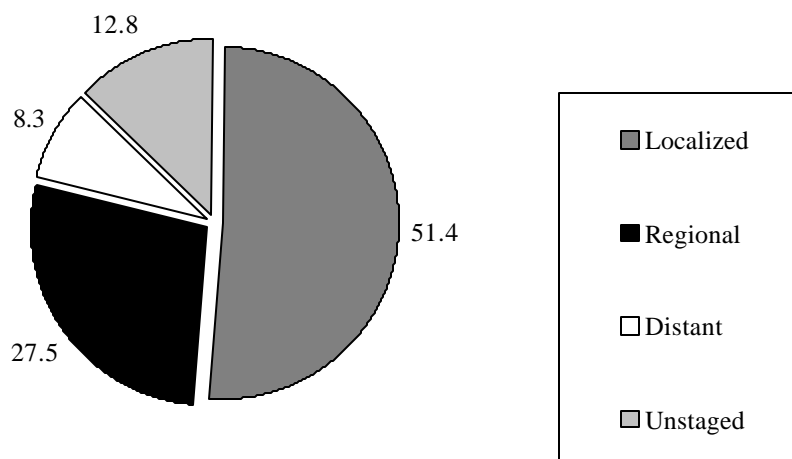
**Figure 1: Cervical Cancer Incidence in the U.S. and New Jersey by Race, 1979-2000\***



Source: New Jersey State Cancer Registry (NJSCR); Rates are per 100,000 and age-adjusted to the 2000 US standard.

\*Incidence rates from the NJSCR for the year 2000 are preliminary.

**Figure 2: Stage at which Invasive Cervical Cancer was Diagnosed in New Jersey, by Percentage, in the year 2000\***



Source: New Jersey State Cancer Registry (NJSCR); Age-adjusted for the 2000 U.S. standard population.

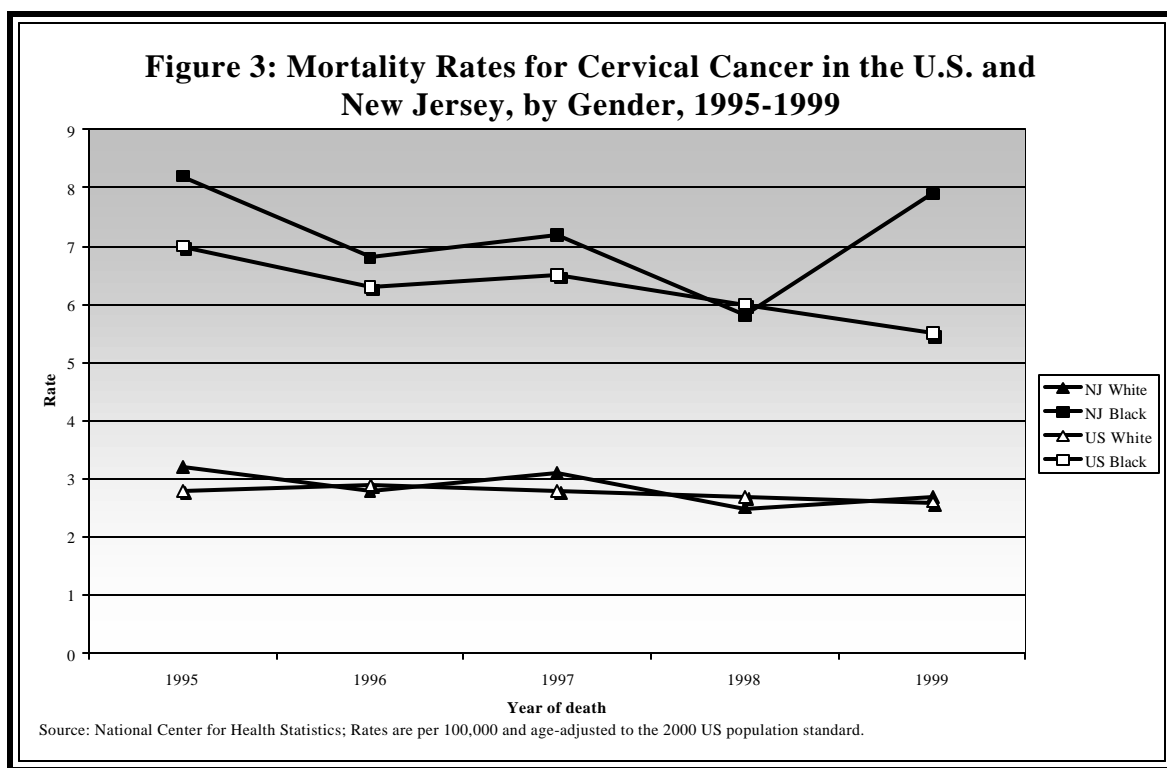
\*Data from the NJSCR for the year 2000 are preliminary.

Note: Data for cervical cancer in situ are not available.

**Mortality.** Mortality rates from cervical cancer in New Jersey and the U.S. generally have declined since 1995. Despite the overall decline in cervical cancer mortality in New Jersey, rates among black women were more than twice as high as the rates among white women. In 1999, the New Jersey mortality rates were 2.7 per 100,000\*\* in white women and 7.9 per 100,000\*\* in black women (Figure 3).

The New Jersey State Cancer Registry's report on cancer among Hispanics in

New Jersey included data on mortality. The patterns vary from those reported on incidence. The age-adjusted cervical cancer mortality rate among Hispanics during 1990-1996 was 4.1 per 100,000 Hispanic women, compared to 2.3 among white and 6.3 among black women. The cervical cancer mortality rate among Hispanics is lower than among blacks, while the reverse is true for cancer incidence. This pattern is consistent with that observed for the rest of the U.S.



**Screening.** Although the screening rates for women reported in various national studies are generally high, they vary across subgroups. Women at highest risk for cervical cancer are least likely to utilize screening (25). National data from the 2000 Behavioral Risk Factor Surveillance Survey (BRFSS) indicate that 70.5% of all women aged 18 years and over reported having had a

Pap test within the previous year, and 87.4% reported having had one within the previous three years. New Jersey reported rates for having had a Pap test within the past three years are lower for white women (88.1%) than for black women (89.6%) or Hispanic women (94.8%). The proportion of women who report having had a Pap test within the past three years begins to decline after age 50;

\*Incidence rates for the year 2000 data from the New Jersey State Cancer Registry are preliminary.

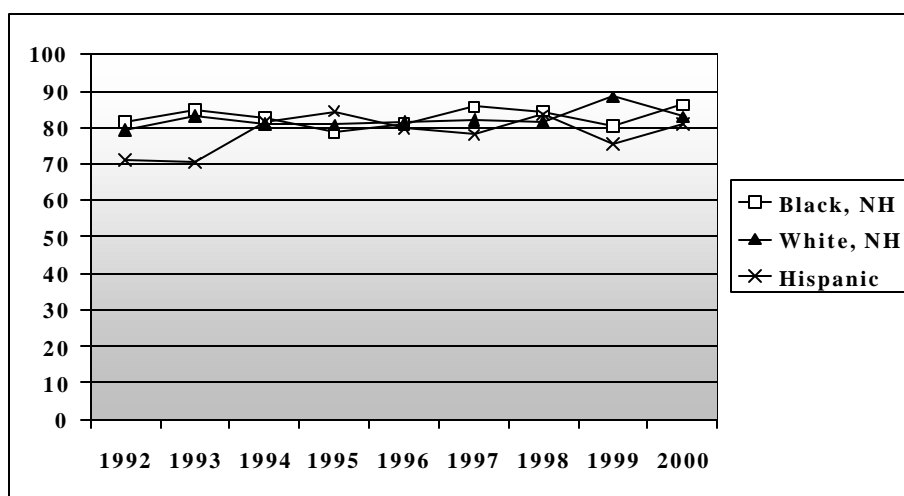
\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

rates are 95% for women 18 to 49, but 89.2% for women 50 to 59, 87.0% for women 60 to 64, and only 71.52% for women aged 65 or older (26).

The high rates of screening in all populations (Figures 4 and 5) are not adequate due to the effectiveness of the Pap test in reducing incidence and mortality from cervical cancer. Although New Jersey black women report

receiving Pap tests at approximately the same rate as white women, the incidence and mortality rates of invasive cervical cancer are much higher in black women. Equal targets have been set by Healthy New Jersey 2010 for all tracked populations to decrease the disparity in the incidence rate of cervical cancer discovered at the more serious late stage.

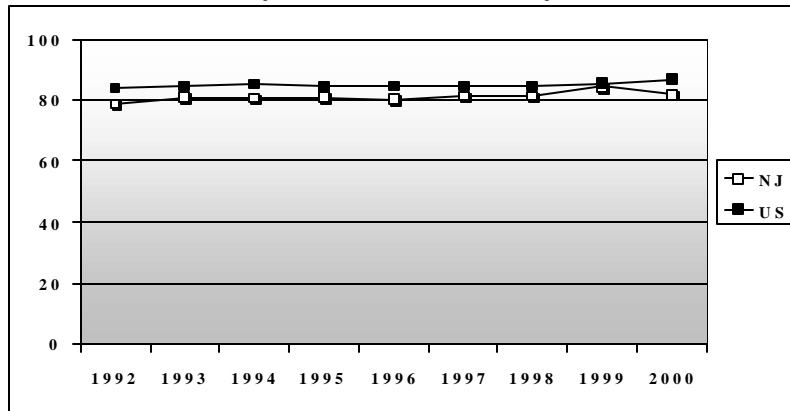
Figure 4: Percent New Jersey Women, with uterine cervix, 18 & older, Pap Smear within 3 years



Source: BRFSS



Figure 5: Percent of women with uterine cervix, 18 and older, who had a Pap smear in the last 3 years, New Jersey and U.S.



Source: BRFSS

### WHAT CAN BE DONE ABOUT CERVICAL CANCER IN NEW JERSEY

To lower cervical cancer incidence and mortality rates, it will be necessary to address barriers to screening and follow-up care to better understand who is contracting cervical cancer in New Jersey and why.

To these ends, the Cervical Cancer Workgroup of the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey has devised strategies that includes numerous opportunities for those from high-risk populations to work side by

side with representatives of medical specialties, nursing, allied health professional groups, voluntary health organizations, healthcare systems, public health entities, and other interested parties to address screening barriers.

The Cervical Cancer Workgroup believes that the accomplishment of the goals, objectives, and strategies outlined in this chapter will have a positive and lasting impact on the health of the affected populations and, ultimately, will lower the social, personal, and economic toll cervical cancer exacts from the citizens of New Jersey.

Below are the Healthy New Jersey 2010 goals relating to cervical cancer.

**Healthy New Jersey Goal 1: Increase the percentage of women aged 18 and over with intact cervix uteri who had a Pap test within the past two years to 75.0% for females 65+, and 85.0% for all other groups, by 2010.**

**Table 1. Baseline data and projected target rates to increase the percentage of women who had a Pap test in the past two years.**

Populations	1997-1999 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total	78.6	85.0	+8.1	90.0	+14.5
White non-Hispanic	79.9	85.0	+6.4	90.0	+12.6
Black non-Hispanic	80.3^	85.0	+5.9	90.0	+12.1
Asian/Pacific Islander	#	#	#	#	#
Hispanic	74.0^	85.0	+14.9	90.0	+21.6
Females 65+	62.7^	75.0	+19.6	85.0	+35.6

Source: Healthy New Jersey 2010

^ Estimate has a relatively large standard error of more than two percent

# Data are statistically unreliable

**Healthy New Jersey Goal 2: Reduce the age-adjusted incidence rate of invasive cervical cancer in females per 100,000 standard population to 5.4, by 2010.**

**Table 2. Baseline data and projected target rates to reduce the age-adjusted incidence rate of invasive cervical cancer.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	8.6	5.4	-37.2	2.0	-76.7
White age-adjusted	8.0	5.4	-32.5	2.0	-75.0
Black age-adjusted	13.9	5.4	-61.2	2.0	-85.6
Asian/Pacific Islander Age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#

Source: Healthy New Jersey 2010

# Data are statistically unreliable

**Healthy New Jersey Goal 3: Reduce the age-adjusted death rate from cervical cancer per 100,000 standard population to 1.0 for all females (age-adjusted), 1.0 for white females (age-adjusted), 2.9 for black females (age-adjusted), and 5.0 for females age 65+, by 2010.**

**Table 3. Baseline data and projected target rates to reduce the age-adjusted death rate from cervical cancer.**

<b>Populations</b>	<b>1998 Baseline Data</b>	<b>Target</b>	<b>Percent Change</b>	<b>Preferred 2010 Endpoint</b>	<b>Percent Change</b>
Total age-adjusted	2.0	1.0	-50.0	0.5	-75.0
White age-adjusted	1.8	1.0	-44.4	0.5	-72.2
Black age-adjusted	3.7	2.9	-21.6	0.5	-86.5
Asian/Pacific Islander Age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#
Women 65+	7.8	5.0	-35.9	0.5	-93.6

*Source: Healthy New Jersey 2010*

*# Data are statistically unreliable*

In support of the Healthy New Jersey 2010 goals for cervical cancer, the recommendations of the Cervical Cancer Workgroup are summarized below for the following five topic areas in priority order:

- Access to Care
- Public Awareness and Education
- Patient Awareness and Education
- Professional Awareness and Education
- Research

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## GOALS, OBJECTIVES AND STRATEGIES

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### ACCESS TO CARE

Cervical cancer incidence and mortality can be reduced effectively through early detection using the Pap test. The decline in death rates from cervical cancer in the United States has been widely attributed to the use of Pap smears for early detection (27). The Pap test is routinely performed (28) by a wide range of health professionals, obstetrician/gynecologists, family physicians, internists, nurse practitioners, physicians assistants, certified nurse midwives, and nurses working in hospitals, clinics, offices, and industrial settings in private and public sectors (28).

New Jersey Public Law, Chapter 415, Laws of 1995 requires health service, hospital service, and medical service corporation contracts, as well as group health insurance policies (providing hospital or medical expense benefits for groups with greater than 49 persons), to provide coverage for Pap tests (29;30). This law also applies to health maintenance organizations in the state.

Additionally, NJCEED sites provide free cervical cancer screening to those who qualify (Appendix E). However, as discussed above, many New Jersey women are not being screened consistently (Figure 3).

A recent study conducted in New Jersey identified reasons women were not being screened for cervical cancer. Barriers include lack of awareness of risk factors, cost, and feelings of embarrassment and discomfort related to the Pap test. Many women failed to recognize age as a risk factor and also reported that women in the higher age groups think they are too old to contract cervical cancer (31). This revelation is reflected in the decrease in screening rates after age 50. In a

report published by the New Jersey Hospital Association, hassles with the healthcare system, prevention not being a priority, inconvenience of professional services, language, transportation, childcare, and cultural sensitivity were identified as barriers for New Jersey women (32). (Chapter 4.1 Access and Resources offers additional detail about access issues in New Jersey.) Similar barriers were also identified in nationwide studies and varied across subpopulations – lack of knowledge about cervical cancer and the need for regular screening, fear of finding cancer, and embarrassment about screening are negatively associated with screening (27;33). Another study concludes that access to care is a confounding variable when analyzing the impact of race on disease (34).

In addition to identifying access barriers to cervical care, we need to better understand who and where populations are that are not receiving adequate care. Although some data have been compiled stratifying for each type of cancer the incidence, prevalence, treatment access, mortality, etc. by age, race, gender, and geographic location, these data are largely incomplete (35). Existing data do not permit all factors to be simultaneously assessed, and summary measures frequently hide vast disparities within subgroups, which may be amenable to intervention and improvement. Population access dramatically differs within New Jersey and linking data sources into a comprehensive database, as well as analytic work targeting those subgroups, will provide detailed data to target those most in need of services. The Cervical Cancer Workgroup proposes that populations at highest risk in New Jersey be identified and investigated to determine why they are not being screened for cervical cancer (2;36).

Once the high-risk populations for New Jersey have been identified, specific programs for screening, education, and treatment must be identified or developed. Specific populations without direct access to cervical cancer screening can be identified and solutions developed. Recognizing that

this plan is merely a beginning to reduce cervical cancer incidence and mortality by increasing screening rates, the Cervical Cancer Workgroup proposes the following goal, objectives, and strategies to improve access.

**GOAL CE-1:**

**To improve access to cervical cancer screening in New Jersey.**

**Objective CE-1.1:**

To locate populations not being screened for cervical cancer in New Jersey.

**Strategies:**

- (CE-1.1.1) Use Geographic Information Systems (GIS) technology and other appropriate data to locate population subgroups with a high risk for developing cervical cancer.
- (CE-1.1.2) Identify barriers to cervical cancer screening in New Jersey by reviewing the literature for barriers that have been identified in the state and developing and implementing pilot studies (where needed) to investigate additional barriers that exist, especially for the populations at increased risk identified in Strategy CE-1.1.1.

**Objective CE-1.2:**

To increase access to cervical cancer screening and treatment for New Jersey populations identified as high risk.

**Strategies:**

- (CE-1.2.1) Develop and evaluate the effectiveness of specific solutions to help individuals overcome the cervical cancer screening and treatment barriers identified above.
- (CE-1.2.2) Identify and refer New Jersey populations to existing programs for screening, education, and treatment for cervical cancer.

- (CE-1.2.3) Develop solutions for those not qualified for existing New Jersey programs, so they can obtain Pap smears/pelvic exams and/or treatment by seeking additional funding, finding sources of care, and finding sources of insurance.

## **PUBLIC AWARENESS AND EDUCATION**

Awareness of risk factors was identified earlier as a barrier to cervical cancer screening in New Jersey women. In the previously mentioned New Jersey study, women failed to recognize age as a risk factor and reported that many women in higher age groups think they are too old to contract cervical cancer. Almost all study participants reported that some older women believe a woman is not at risk for cervical cancer and does not need to have a Pap test if she has gone through menopause. Although participants correctly linked cervical cancer with sexually transmitted disease, some mistakenly believed that personal hygiene was a factor in cervical cancer causation. Additionally, they noted that women might also think Pap tests are necessary only if they are having sexual relations (31). Although the study may not be representative of all New Jersey women because many were qualified for NJCEED, the study results provide a good example of misconceptions and barriers to screening among New Jersey women.

A national study asking questions about cancer to measure knowledge revealed that only 86% of the public had “heard of” cervical cancer, compared to 96% who had heard of skin cancer and 97% who had heard of lung cancer (37). Data from BRFSS indicate that nearly 18.1% of New Jersey females (over 18 with an intact cervix) have not had a Pap test in the past three years. Additionally, the screening rate has remained the same over the past several years (Figures 6,7). Clearly, the effectiveness of the Pap test in reducing cervical cancer incidence and

mortality is not evident from the surveyed populations.

To combat the lack of education and awareness in New Jersey, NJCEED is one of several programs that provide education about cervical cancer screening and treatment. In 2001, funding emphasis was on education for risk factors, screening/early detection practices, and treatment regimens in order to provide New Jerseyans with sufficient information to make informed choices about cancer screening and treatment (38). Additional research has shown that the rate of cervical cancer screening can be increased through worksite education programs and peer interventions (39).

Although educational resources exist, services are provided only to specific populations. There is no comprehensive, consistent message for cervical cancer screening and treatment. One example is a New Jersey study which revealed that many women do not obtain Pap tests because inconsistency in the guidelines caused confusion (31).

To address these issues, the Cervical Cancer Workgroup proposes that a public education program be developed and disseminated to all New Jersey women. In conjunction with the National Institutes of Health, it is recommended that community-based approaches be used to reach diverse populations and that these approaches include reliance upon community leaders and community members to assess attitudes and concerns prior to instituting education programs. Culturally sensitive and linguistically compatible staffing for outreach and education programs is a key component (2).

In addition to educational programs, the Workgroup proposes that insurance companies educate their clients about screening, which will ultimately reduce health care costs by preventing invasive cervical cancer or diagnosing cervical cancer at earlier stages. The Workgroup also proposes that patient compliance with screening guidelines, a behavior-driven issue, can be ingrained at an earlier age by educating school-aged

young women using progressive and appropriate materials.

Most importantly, the Cervical Cancer Workgroup notes that these steps represent only a beginning in a comprehensive approach to cancer prevention and control in New Jersey and that through evaluation of programs, and continuous quality improvement methods will help the public education component of this plan evolve.

#### **GOAL CE-2:**

**To increase public awareness and education about cervical cancer among all women, especially increased risk populations.**

#### **Objective CE-2.1:**

To educate the public about cervical cancer by using appropriate educational materials and programs to reach all women, especially those at increased risk (identified in the Access section above).

#### **Strategies:**

- (CE-2.1.1) Identify and develop (where needed) educational materials and programs that are effective for populations with an increased risk of cervical cancer, including media campaigns, key spokespeople, and enhancing events during Cervical Cancer Awareness Month (currently in January).
- (CE-2.1.2) Outreach to increased-risk populations with cervical cancer educational materials and programs by partnering with key people, other social/intervention/entitlement programs, federal and state agencies, local organizations and businesses that work within the areas and populations identified.
- (CE-2.1.3) Design a progressive, age-appropriate cancer prevention core curriculum in schools, including the importance of cervical cancer screening and early detection, especially targeting populations at increased risk as identified above.
- (CE-2.1.4) Encourage insurance companies to educate their clients, especially high-risk individuals, about cervical cancer screening and early detection through the use of reminder systems and distribution of educational materials.

## **PATIENT AWARENESS AND EDUCATION**

**W**hile public education is important to increase awareness of cervical cancer and the need for screening, patient education is equally important to increase awareness of rescreening, follow-up, and treatment options.

Receiving notification of abnormal test results often has negative psychological consequences on the patient and, unless addressed, may result in failure to comply with both treatment and future screening tests. Special intervention procedures that make use of telephone calls or in-person visits to find and remind women to return for follow-up have obtained compliance rates of 33% to 95% (40). Barriers, such as cost of follow-up treatment, beliefs about cancer, lack of trust in the medical system, lack of access to transportation, and staff attitudes at healthcare facilities, all contribute to patients' reactions to abnormal test results and may influence whether follow-up recommendations are followed (41;42).

Educational resources specifically addressing the importance of rescreening, timely follow-up, and treatment options must consider the patient as the receiver of the communications. Consideration should be given to developing and using strategies to communicate with patients with varying demographic characteristics, such as years of education and literacy. The communication provided could greatly affect the psychosocial impact on the woman of hearing the results and her willingness to seek additional care (7). The Cervical Cancer Workgroup proposes that different modes of education be utilized to address all populations, including media, computer, and paper-based materials.

There is strong evidence that women experience significant anxiety and stress when informed of abnormal results (25). The method and manner of notification can often mediate these reactions. Upon receipt of laboratory results, the provider has the responsibility of informing the patient. The usual methods of notification are in writing, over the telephone, or in person. Written forms, usually letters or post cards, may not be understandable to the patient because of the reading level of the message or because of terminology that is foreign or not clearly defined (40). Telephone counseling is more costly, but could be used in explaining serious cases and might reduce the chance of severe psychological reactions to test results. Method of communication should be carefully considered and measured for effectiveness when reaching out to women about follow-up care.

Another method to improve rescreening and follow-up is to increase the effectiveness of follow-up after abnormal Pap tests. Research has shown that cognitive interventions utilizing interactive counseling improve compliance by 24% to 31%. Behavioral interventions, such as patient reminders, increase follow-up by 18% (43).

To begin to increase patient awareness about the importance of cervical cancer rescreening, follow-up care, and treatment options, the Cervical Cancer Workgroup proposes that patients be educated using multimedia interventions that are updated continuously. Additionally, the Workgroup proposes that current systems for Pap test result notification and patient reminder systems be evaluated and the best systems shared with healthcare professionals in New Jersey. To accomplish these goals, the Cervical Cancer Workgroup recommends the following goal, objective, and strategies as important next steps.



**GOAL CE-3:**

**To improve patient education about cervical cancer, screening, follow-up care, and treatment options, including clinical trials.**

**Objective CE-3.1:**

To educate patients about cervical cancer, screening guidelines, follow-up care, and treatment options at all medical facilities where they may seek medical attention, including but not limited to, healthcare providers, hospitals, clinics, and health departments.

**Strategies:**

- (CE-3.1.1) Make educational brochures and posters on guidelines, risk factors, and symptoms for cervical cancer available to appropriate healthcare professionals for display at medical facilities. Provide contact information for reordering.
- (CE-3.1.2) Review cervical cancer educational brochures and posters annually in order to continuously update materials developed in Strategy CE-3.1.1 with new information as needed.
- (CE-3.1.3) Develop and distribute a resource listing of cervical cancer information sources (including clinical trial information) to all medical facilities on an annual basis.
- (CE-3.1.4) Review the methods that different medical facilities and laboratories use to notify patients of their Pap smear results. Determine the method easiest for patients to understand, and share the study results with all medical facilities and laboratories for possible implementation.
- (CE-3.1.5) Survey appropriate medical facilities for the use of an electronic follow-up/diagnostic Pap test reminder. Based on survey findings, identify and encourage the appropriate medical facilities to use an electronic Pap smear reminder system.

**PROFESSIONAL AWARENESS AND EDUCATION**

The Cervical Cancer Workgroup identified Professional Education as the third arm of the education recommendations. Issues identified were the importance of physician referrals and the high error rate of Pap tests.

To improve cervical cancer incidence and mortality in New Jersey, the Cervical Cancer Workgroup proposes solutions to each of these issues.

It has been estimated that 40% or more of women with abnormal Pap smears fail to comply with follow-up recommendations (40). Appropriate follow-up and treatment

may not occur because of issues of patient education and understanding, provider promotion, access, or cost (7).

A physician recommendation is a very strong motivator for obtaining a Pap test (44;45). A recent study of national trends in the use of preventive healthcare showed that most women who did not receive a Pap test did have recent contact with a physician (46). These findings suggest that, although women are visiting physicians and are open to receiving medical advice, recommendations are not provided consistently. A literature review identified reasons why primary care providers do not adhere to cervical cancer screening guidelines. Reasons include *provider characteristics*, such as knowledge of the guidelines, specialty, gender, time constraints, forgetfulness, and inconvenience; *patient characteristics*, such as age and perceived refusal; and *provider constraints*, such as lack of supplies and the cost of the test (46). For these reasons the Cervical Cancer Workgroup proposes that professionals be given additional education and materials to increase their awareness of cervical cancer.

Furthermore, it appears there are important differences in screening rates among provider specialties (47). Women receiving care from nurses or from obstetricians/gynecologists are most likely to report having had a recent Pap test. Those receiving care from an internist are least likely to report being screened. If a woman is being seen regularly for more acute, life-threatening care such as blood pressure or diabetes, her provider may also be less likely to recommend a Pap test because of the added inconvenience to the patient and lack of time during the clinic visit to do a Pap test (28). Many interventions have been found to be successful in increasing screening rates among women receiving medical care. These include opportunistic screening (recom-

mending Pap test screening when a woman is in an emergency room, provider's office, or hospital) or prompts, such as stickers on patient charts (48). Studies have been done of invitation and recall systems and identified specific factors that appear to increase rates of utilization. These include, for example, clearly explaining the benefits of screening and using personal contact with healthcare staff to allay anxiety (7;25). The Cervical Cancer Workgroup recommends that a comprehensive cancer assessment be a standard component of the patient chart to assure that patients are receiving cancer education and screenings as appropriate.

Any screening program that focuses solely on "percent population reached" is concentrating efforts on only half of the problem. The other arm of that program must emphasize accuracy in diagnosis. A single Pap test has a false-negative rate estimated to be between 15% and 30% (2;49). One-half of the false negatives are due to inadequate specimen sampling, and the other half are attributed to a failure to identify the abnormal cells or to interpret them correctly (2;36;50). At least one-half to two-thirds of false negatives are the result of patient conditions present at the time of sample collection and submission and the skill and knowledge of the individual who obtains the sample (51). Examples include incomplete sampling of the transformation zone, a poorly prepared slide with drying artifact or clumping of cells, and failure of the cytotechnologist to detect the presence of abnormal cells on the slide. Thus, encouraging improvements in sampling technique and laboratory accuracy represent an opportunity to reduce incidence and mortality from cervical cancer.

Attention has been focused on quality control in cytopathology laboratories in an attempt to reduce the problem of false negative Pap smear tests (50). There must be an accurate

and timely reading of the smear, including a clear report of results to the provider. After collection, the Pap test sample is sent with a clinical requisition form to the laboratory for interpretation. The quality of the reading of the smear is primarily dependent upon the level of expertise of those interpreting the slide. Cytotechnologists are in high demand and short supply and, because of salary competition, the workforce is quite mobile. Any shortages are likely to impact negatively on the turn-around time for receiving Pap test results and can possibly overburden existing staff (7;50). The Clinical Laboratory Improvement Amendments of 1988 applied workload limits to slides screened per hour in any given 24-hour period. Cytotechnologists may examine up to 100 slides per 24 hours (average 12.5 slides/hour) and in not less than eight hours (51). In accordance with recommendations by the Agency for Healthcare Research and Quality, the Cervical Cancer Workgroup proposes that screening rates be monitored to ensure compliance with the workload limits established for each individual (50).

One critical aspect of quality assurance in cervical cytology is communication of cytopathologic findings to the referring physician in unambiguous diagnostic terms that have clinical relevance. Terminology currently used is varied, resulting in confusion about the clinical implications of the report. The Bethesda System for reporting the results of cervical cytopathology was developed as a uniform system of terminology that would provide clear guidance for clinical

management (52;53). More than 90% of U.S. laboratories use some form of the 1991 Bethesda System in reporting cervical cytology (54). In 2001, the Bethesda System was updated to reflect increased utilization of new technologies and findings from research (55). In accordance with the National Institutes of Health, the Cervical Cancer Workgroup encourages the use of the Bethesda System 2001 as a method to increase uniformity of Pap smear reporting and decrease error (2).

Clinical Laboratory Improvement Amendments of 1988 regulations specify that at least 10% of samples interpreted as negative by each cytotechnologist be rescreened by a pathologist or a qualified supervisory cytotechnologist prior to reporting. Specimens from women considered to be at increased risk for cervical cancer must be included in the review process (51). Recent developments (56) in specimen processing and interpretation may substantially improve the Pap smear as a diagnostic test for cervical cancer and cancer precursors. Thin-layer cytology aims primarily to fix sampling error, whereas computerized rescreening targets detection error (50). Thus, the Cervical Cancer Workgroup recommends that continuous quality improvement methods be increased to further decrease error rates.

By using the following goal, objectives, and strategies to educate providers and decrease error rates, the Cervical Cancer Workgroup hopes to decrease incidence and mortality from Cervical Cancer in New Jersey.

<b>GOAL CE-4:</b>
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**To increase the awareness of healthcare professionals concerning cervical cancer, risk factors, screening guidelines, follow-up, and treatment options.**

**Objective CE-4.1:**

To educate healthcare professionals about the importance of cervical cancer, screening, risk factors, follow-up, treatment options, and cultural sensitivity.

**Strategies:**

- (CE-4.1.1) Develop and disseminate cervical cancer educational brochures appropriate for healthcare providers.
- (CE-4.1.2) Partner with professional organizations to offer incentives to healthcare professionals for completion of cervical cancer educational modules/in-services. This can be in the form of CME credits and/or recognition.
- (CE-4.1.3) Survey general practitioners, obstetricians/gynecologists, family practice physicians, internists, and advanced practice nurses to elicit the providers who administer a “health assessment survey” to capture patient history of pap smears, as well as other cancer screening and regular check-ups. Based on survey findings, develop and distribute a standardized “health assessment survey” to all general practitioners, obstetricians/gynecologists, family practice physicians, internists, and advanced practice nurses for possible adoption.
- (CE-4.1.4) Disseminate clinical guidelines for cervical cancer screening and follow-up to appropriate healthcare providers.

**Objective CE-4.2:**

To decrease the error rate of Pap smears.

**Strategies:**

- (CE-4.2.1) Educate clinicians on optimal conditions for obtaining a Pap smear and appropriate methods for collecting and handling Pap smears.
- (CE-4.2.2) Recommend legislation that the maximum number of slides read by each cytotechnologist be decreased from 100 slides per 24-hour period.
- (CE-4.2.3) Identify areas where there is a lack of cytotechnologists and recommend training and continuing education programs to the appropriate agencies.

- (CE-4.2.4) Recommend that laboratories standardize the system for reporting cervical cytopathology results using Bethesda 2001.
- (CE-4.2.5) Support continuous quality improvement methods to reduce the Pap smear error rate, including methods such as computerized rescreening.

## **RESEARCH**

Cervical cancer literature has noted that research is warranted in many areas, including the areas of behavior change, improving accuracy and interpretation of cytologic sampling techniques, and screening methods (2). At the research forefront of prevention and treatment of cervical cancer is the development and testing of prophylactic and therapeutic vaccines against HPV (2).

Clinical trials are the major avenue for discovering, developing, and evaluating new therapies. However, only about 3% of all

adult cancer patients participate in clinical trials. It is important to increase physician and patient awareness of, and participation in, clinical trials if we are to test new treatments more rapidly, find more effective treatments, and broaden the options available to patients (57).

Research must be conducted to learn why New Jersey women do not participate in clinical trials. Then, solutions to the barriers must be addressed. The Cervical Cancer Workgroup suggests the following goal, objectives, and strategies as next steps.

### **GOAL CE-5:**

**To foster the development of and to improve awareness of clinical research for cervical cancer and increase participation in clinical research available in New Jersey and/or available to New Jersey residents.**

#### **Objective CE-5.1:**

To identify existing research being done for cervical cancer available in New Jersey and/or available to New Jersey residents.

#### **Strategies:**

- (CE-5.1.1) Contact pharmaceutical companies and medical organizations to identify current clinical trials for cervical cancer in New Jersey.
- (CE-5.1.2) Identify a department within the state that practitioners can use as a resource for identifying cervical cancer clinical trials in New Jersey for which their patients are eligible.

**Objective CE-5.2:**

To attract and encourage participation in new and existing clinical research in New Jersey and/or available to New Jersey residents, especially in preventive and treatment measures in cervical cancer.

**Strategies:**

- (CE-5.2.1) Link the state website to agencies such as [emergingmed.com](http://emergingmed.com) to make cervical cancer clinical trials more accessible to New Jersey residents.
- (CE-5.2.2) Determine reasons for lack of participation in cervical cancer clinical trials.
- (CE-5.2.3) Collaborate with key associations/organizations to publicize cervical cancer clinical trials in New Jersey.
- (CE-5.2.4) Outreach to healthcare providers and community leaders to improve client participation in cervical cancer clinical trials.
- (CE-5.2.5) Collaborate with the New Jersey Commission on Cancer Research and others to support cervical cancer clinical trials in New Jersey.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: CE-1.1.1; CE-1.1.2; CE-1.2.1; CE-1.2.2; CE-1.2.3; CE-2.1.1; CE-2.1.2; CE-2.1.3; CE-2.1.4; CE-3.1.1; CE-3.1.2; CE-4.1.4; CE-5.1.1; CE-5.1.2; CE-5.2.1; CE-5.2.2; CE-5.2.3; CE-5.2.4; CE-5.2.5

New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection (NJCEED): CE-1.1.1; CE-1.1.2; CE-1.2.1; CE-1.2.2; CE-1.2.3; CE-2.1.1; CE-2.1.2; CE-3.1.1; CE-3.1.2; CE-4.1.1; CE-4.1.2; CE-4.1.3; CE-4.1.4; CE-4.2.1; CE-4.2.4

## CERVICAL

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Improve access to cervical cancer screening	1.1: Locate populations not being screened	CE-1.1.1						
		CE-1.1.2						
	1.2: Increase access to populations identified as high risk	CE-1.2.1						
		CE-1.2.2						
		CE-1.2.3						
2: Increase public awareness and education, especially with high-risk populations	2.1: Educate the public, especially those at increased risk	CE-2.1.1						
		CE-2.1.2						
		CE-2.1.3						
		CE-2.1.4						
		CE-2.1.5						
3: Improve patient education	3.1: Educate patients regarding screening guidelines, care and treatment	CE-3.1.1						
		CE-3.1.2						
		CE-3.1.3						
		CE-3.1.4						
		CE-3.1.5						
4: Increase awareness of healthcare professionals	4.1: Educate healthcare professionals	CE-4.1.1						
		CE-4.1.2						
		CE-4.1.3						
		CE-4.1.4						
	4.2: Decrease Pap smear error rate	CE-4.2.1						
		CE-4.2.2						
		CE-4.2.3						
		CE-4.2.4						
5: Increase awareness and participation in clinical trials	5.1: Identify existing research	CE-5.1.1						
		CE-5.1.2						
	5.2: Attract/encourage clinical trial participation	CE-5.2.1						
		CE-5.2.2						
		CE-5.2.3						
		CE-5.2.4						
		CE-5.2.5						

Target Completion Date

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## CHAPTER 8. Colorectal Cancer

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## COLORECTAL CANCER

### IMPORTANCE OF COLORECTAL CANCER FOR CANCER PREVENTION AND CONTROL

Colorectal cancer is the third most common cancer among both men and women in the United States. The American Cancer Society estimates that in 2002 in the United States there will be 148,300 new cases of colorectal cancer diagnosed and 56,600 deaths, accounting for almost 11% of all cancers among men and 12% among women. Colorectal cancers account for an almost equal proportion of cancer deaths (10% among men and 11% among women). Nationwide, the lifetime risk for developing colorectal cancer is approximately 1 in 18 persons. Between 1985 and 1997 colorectal cancer incidence rates declined 1.6% per year. Mortality rates from colorectal cancer have also declined, at about 1.8% per year, as a result of decreasing incidence and improvements in survival rates (1)(2;3).

### COLORECTAL CANCER IN NEW JERSEY

**Incidence.** Consistent with US colorectal cancer incidence rates, rates in New Jersey have declined since 1979 among white males, white females, and black females but has increased among black males (Figure 1). Although the number of colorectal cancer cases is approximately equal for men and women (principally because women live longer than men) (1), men have consistently had higher incidence rates than women,

regardless of race. According to preliminary 2000\* data from the New Jersey State Cancer Registry, the incidence rate of colorectal cancer among New Jersey men (all races combined) was 76.0 per 100,000\*\*; the incidence rate for white males was 76.0 compared to 80.3 per 100,000 for black males. Incidence rates among New Jersey females (all races combined) was 53.6 per 100,000\*\*; the incidence rate for white females was 52.6 compared to 56.4 per 100,000\*\* for black females in 2000\* (4). The American Cancer Society estimates that, in 2002, 4,900 new colorectal cancer cases will be diagnosed in New Jersey (1).

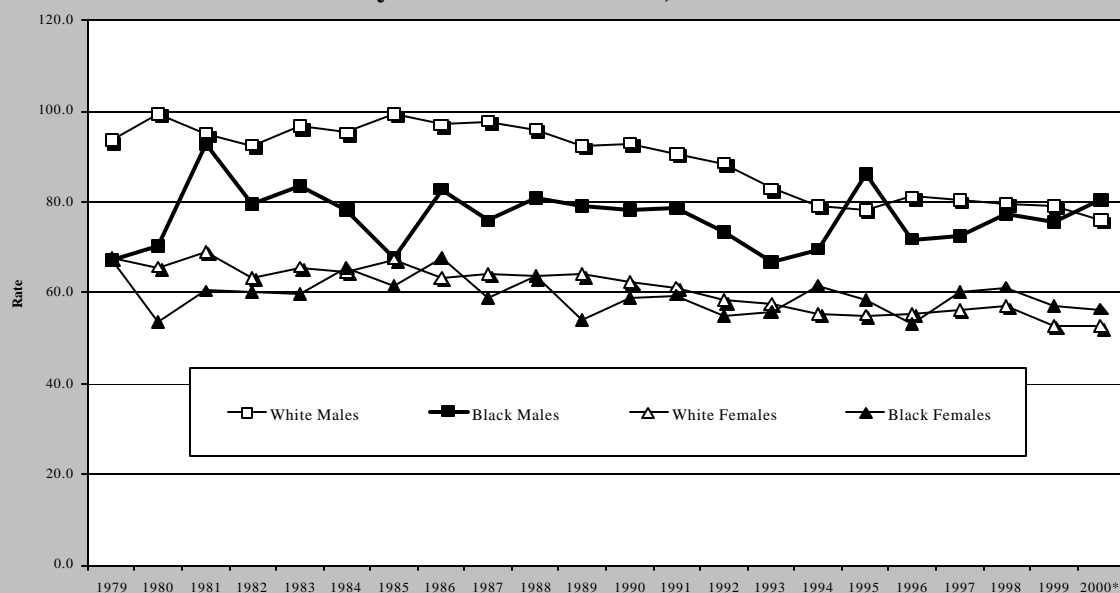
**Mortality.** Mortality from colorectal cancer comprises approximately 12% of all cancer deaths in New Jersey (5). According to the colorectal cancer mortality rates from the National Center for Health Statistics, rates for New Jersey males (all races combined) decreased from 33.2 per 100,000\*\* in 1995 to 28.4 per 100,000\*\* in 1999 (Figure 2). This decrease was evident in mortality rates for both white males and black males. Similarly, mortality rates for New Jersey females (all races combined) decreased from 22.2 per 100,000\*\* in 1995 to 20.1 per 100,000\*\* in 1999 (Figure 2). This decrease was evident in both white females and black females in New Jersey. The American Cancer Society estimates that, in 2002, there will be 1,900 deaths in New Jersey due to colorectal cancer (1).

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\*Incidence rates for the year 2000 data from the New Jersey State Cancer Registry are preliminary.

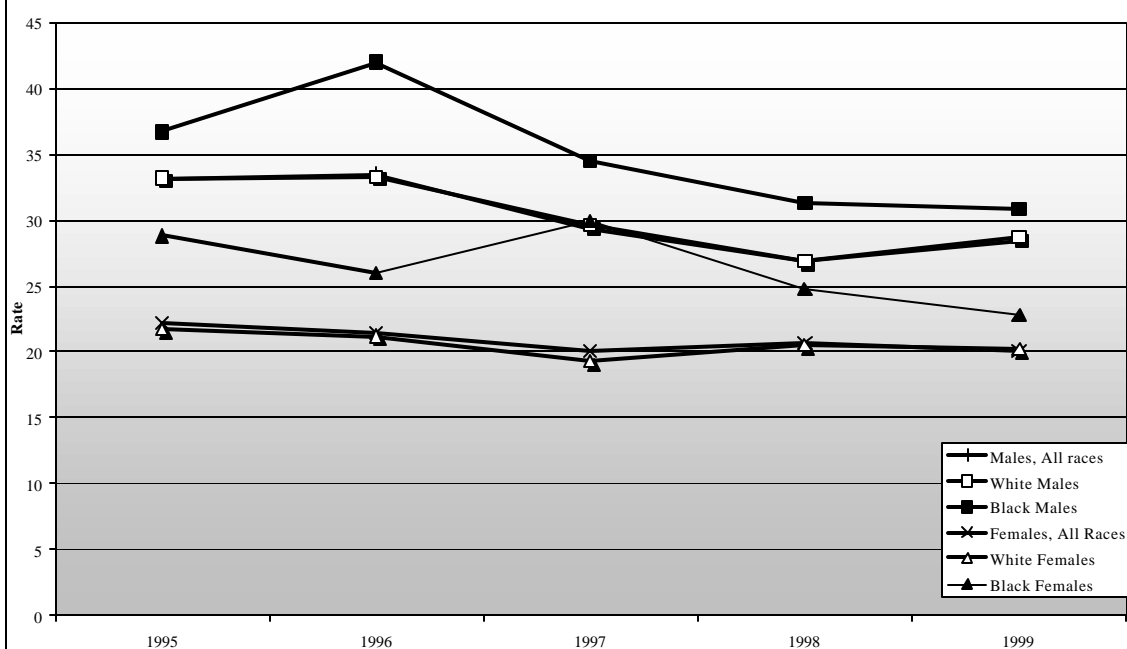
\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

**Figure 1: New Jersey Incidence Rates for Colorectal Cancer by Race and Gender, 1979-2000\***



Source: New Jersey State Cancer Registry (NJSCR) ; Rates are per 100,000 and age-adjusted to the 2000 U.S. (5-year groups) standard; \*Incidence rates for the year 2000 data from the NJSCR are preliminary.

**Figure 2: New Jersey Colorectal Cancer Mortality Rates by Race and Gender, 1995-1999**



Source: National Center for Health Statistics; Rates are per 100,000 and age-adjusted to the U.S. 2000 standard population.

**Screening.** While the incidence of colorectal cancer overall is decreasing in New Jersey, cancers of the proximal colon (including the cecum, ascending colon, hepatic flexure, transverse colon, and splenic flexure) are on the rise. Only about 30% of these cases are diagnosed in the early stages when treatment is most effective (6). For this reason, screening and early detection are important factors in decreasing incidence and mortality from colorectal cancer.

Several methods are currently in use to screen for colorectal cancer: digital rectal exam (DRE), fecal occult blood test (FOBT), flexible sigmoidoscopy (flex sig) or sigmoidoscopy, double contrast barium enema (DCBE), and colonoscopy. The DRE examines only a limited portion of the rectum and is not recommended as a screening method when used alone. The FOBT is not

specific to colorectal cancer or polyps, but may be used to determine whether a more specific test is needed. A sigmoidoscopy provides a view of the rectum and part of the distal colon and has been shown to reduce colorectal cancers of that site by up to 59% (6). Only the colonoscopy and double contrast barium enema can provide a view of the entire colon and rectum, and these are therefore the only screening tests able to detect cancers of the proximal colon (7;8). The colonoscopy, however, has higher sensitivity than the DCBE; it has been shown to detect new cancers by up to 66% (9). New screening tests on the horizon include virtual colonoscopy, immunochemical testing, and genetic-based fecal screening (1). See table below for a summary of current colorectal cancer screening options.



**Centers for Disease Control and Prevention  
Current Colorectal Cancer Screening Guidelines  
For Average Risk Individuals Over Age 50\* (1;7;9)**

<b>Test Type</b>	<b>General Frequency**</b>	<b>Benefits</b>	<b>Limitations***</b>
Fecal Occult Blood Test	Every Year	<ul style="list-style-type: none"> <li>• 33% mortality reduction</li> <li>• Low cost</li> <li>• No bowel preparation</li> </ul>	<ul style="list-style-type: none"> <li>• Performed at home and subject to patient error</li> <li>• Not specific for colorectal cancers</li> <li>• Pre-test dietary restrictions</li> <li>• Will miss some polyps</li> <li>• Additional procedures needed if positive</li> </ul>
Flexible Sigmoidoscopy	5 years	<ul style="list-style-type: none"> <li>• 60% mortality reduction from distal colon/rectal cancers</li> <li>• Minimal preparation/discomfort</li> </ul>	<ul style="list-style-type: none"> <li>• No reduction in deaths from proximal colon cancers</li> <li>• Views approx. 1/3 of colon</li> <li>• Small risk of infection or bowel tear</li> <li>• Additional procedures needed if positive</li> </ul>
Colonoscopy	10 years	<ul style="list-style-type: none"> <li>• Provides view of entire colon</li> <li>• 66% reduction of new cancers. Most accurate test for detecting polyps</li> <li>• Can biopsy and remove polyps</li> <li>• Can diagnose other disease</li> </ul>	<ul style="list-style-type: none"> <li>• Can miss small polyps</li> <li>• Sedation needed</li> <li>• Not recommended for patients with advanced age</li> <li>• Subject to provider capability</li> <li>• Potential risk of infection or bowel tears</li> </ul>
Double Contrast Barium Enema	5-10 years	<ul style="list-style-type: none"> <li>• Provides view of the entire colon</li> <li>• Few complications</li> <li>• No sedation needed</li> </ul>	<ul style="list-style-type: none"> <li>• Can miss small polyps</li> <li>• Lower sensitivity to detecting polyps than colonoscopy</li> <li>• Full bowel preparation needed</li> <li>• Additional procedures needed if positive</li> </ul>

\*For average risk individuals. Individuals with increased or high risk should begin screening before age 50. See the Appendix F for more information.

\*\*Suggested frequencies vary and may change as new information becomes available. See the Appendix F for a list of screening guideline resources. Patients should consult a physician to determine the best screening program to meet their needs.

\*\*\*Information on the limitations of screening tests are from both the Centers for Disease Control and Prevention (9) and the American Cancer Society (1).

Although screening and early detection are important in the successful prevention and treatment of colorectal cancer, colorectal cancer screening is less widely used than screening for other cancers. (See table below for the percent of New Jersey residents who have had an FOBT, a sigmoidoscopy, or a colonoscopy.) These numbers reflect the need for efforts to increase education and awareness of colorectal cancer screening and prevention (7).

**Percent of New Jersey Residents Age 50 and Over  
Who have had Colorectal Cancer Screening  
New Jersey versus U.S. by Gender, 1997 and 1999\***

TYPE OF SCREENING	PERCENT OF MALES				PERCENT OF FEMALES			
	1997		1999		1997		1999	
	N.J.	U.S.	N.J.	U.S.	N.J.	U.S.	N.J.	U.S.
Ever had a blood stool test from a home kit?	24.8	27.1	29.3	26.6	32.1	34.1	37.3	35.2
Had a blood stool test from a home kit in the past year?	65.3	47.3	60.5	47.4	56.1	45.9	57.0	47.0
Ever had a sigmoidoscopy/colonoscopy?	34.7	34.6	37.2	-	28.8	30.4	32.0	-
Had sigmoidoscopy/colonoscopy in the past 5 years?	39.3	35.1	21.8	-	27.0	26.8	22.9	-

\*Data are from a sample of people surveyed through the Behavioral Risk Factor Surveillance System, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. U.S. sigmoidoscopy/colonoscopy screening data are not available for 1999.

Below is the Healthy New Jersey 2010 goal relating to colorectal cancer.

**Healthy New Jersey Goal: Reduce the age-adjusted death rate from colorectal cancer per 100, 000 standard population\* to: 10.0 for the total population (age-adjusted), 10.0 for whites (age-adjusted), 14.0 for blacks (age-adjusted) and 122.7 for persons 65+, by 2010.**

**Table 3. Baseline data and projected target rates to reduce the death rate from colorectal cancer**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	12.4	10.0	-19.4	7.0	-43.5
White age-adjusted	12.2	10.0	-18.0	7.0	-42.6
Black age-adjusted	16.3	14.0	-14.1	7.0	-57.1
Asian/Pacific Islander age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#
Persons 65+	143	122.7	-14.2	80.0	-44.1

<sup>#</sup>Data are statistically unreliable.

Source: Healthy New Jersey 2010

In support of the Healthy New Jersey 2010 goal for colorectal cancer, the recommendations of the Colorectal Cancer Workgroup are summarized below for the following topic areas in priority order:

- Awareness and Education
- Treatment

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## GOALS, OBJECTIVES AND STRATEGIES

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### AWARENESS AND EDUCATION

The impact of colorectal cancer on the morbidity and mortality of American citizens, in general, and on New Jersey residents, in particular, is alarming. New Jersey has the highest incidence rate of colorectal cancer in the country for males and the second highest rate for females. The mortality rates show a similar trend (1). Yet despite these statistics, colorectal cancer has not received the attention breast and prostate cancers have.

Colorectal cancers account for approximately 11% of all cancer deaths resulting in 785,000 person years of life lost and costing \$6 billion annually in treatment (10). Without preventive intervention, about 5% to 6% of the population (or 1 in 17 persons) will develop colorectal cancer at some point during their lives (10). The vast majority of colorectal cancers are diagnosed in those over age 50, and men and women are equally affected. Blacks are more likely than other racial and ethnic groups to contract colorectal cancer. While some groups are at increased risk for the disease (such as those with inflammatory bowel disease or certain familial syndromes), most cases develop in individuals with no predisposing risk factors.

It is well established that early detection of cancer through screening tests offers significantly improved chances for survival. Yet despite established screening and treatment guidelines, widespread availability of testing, and widespread agreement among professional societies and the scientific community that screening can prevent colorectal cancer and reduce mortality, screening rates remain relatively low for the population as a whole. The concentration of

particularly low screening rates in certain subgroups (e.g., minorities, the uninsured, and the medically underserved) contributes to higher colorectal cancer mortality in these populations (10-12).

Strong evidence indicates that screening is an effective tool in reducing the incidence and mortality rates of colorectal cancers. In fact, incidence and mortality rates declined 1.6% and 1.8%, respectively, between the years 1985 and 1997 (2). Research suggests that the decline may be due to increased screening and polyp removal preventing progression of polyps to invasive cancers (2;10;12). However, while colorectal cancer screening increased over the past decade, it still lags behind the use of mammography and Pap smear as screening tools (3;11). In the Centers for Disease Control and Prevention's 1999 Behavioral Risk Factor Surveillance System (BRFSS) survey, only 26.1% of New Jersey respondents reported having had a recent FOBT (within the last year) and 35.3% reported having had a recent sigmoidoscopy or colonoscopy (within the preceding five years). These percentages are in stark contrast to the 66.8% of women who reported a mammogram in the last year.

Colorectal cancer has received relatively little publicity, even though it has a well-defined, identifiable, and treatable precursor lesion (13). Cancer screening rates continue to be low among minorities and among groups that lack health insurance or a usual source of care, and large disparities in cancer incidence and mortality across racial and ethnic groups persist (2;3;10;12). Blacks and other minority groups are more likely to be diagnosed with more advanced colorectal cancer than their white counterparts (12). Similarly, persons with limited education and lower

socioeconomic status infrequently participate in screening programs in general and have very low rates of colorectal cancer screening in particular (2;3;14). Colorectal screening must become a focused health initiative, as is already the case with breast and prostate cancer screening. Only through recognition of colorectal cancer as a major health problem will we be able to effectively influence incidence and mortality rates.

To be effective, preventive initiatives focusing on colorectal cancer must be inclusive of the general population as well as those at increased risk for developing colorectal cancer and must include the screening options currently available for the detection of colorectal cancer. Approximately 70% to 80% of all colorectal cancers occur among people at “average risk” (defined as anyone without an identifiable risk factor), and 15% to 20% occur among those with “increased risk” or “high risk” (2;3;10). As cost is often cited as a barrier to screening, accurate and cost-efficient options must be available to the healthcare practitioner as well as to the community. Several screening options exist for cost containment while maximizing the benefits of screening (2). Insurance coverage for age- and risk-appropriate screening must be available in order to reduce the incidence of colorectal cancer and increase the efficacy of screening interventions by identifying early disease for optimal health benefits. Therefore, screening efforts combined with broader educational initiatives must be part of a complete and comprehensive prevention program that integrates age-related screening with the promotion of healthy lifestyles.

Colorectal cancer screening rates are low for a number of reasons. Some reasons are associated with the individual patient. Colorectal cancer and colorectal cancer screening tests are unpopular subjects. The

public views the tests as distasteful and as likely to be painful. Most people know little about the tests and are confused about what test to have and when. Most also report that their doctors do not talk to them about colorectal cancer or their screening options. Other reasons for low colorectal cancer screening rates are associated with healthcare providers. Providers cite a lack of training and/or experience in testing, lack of time to discuss the subject with their patients, a desire to avoid inconveniencing their patients, and concern that the tests are not effective. Further reasons these tests are not performed include inadequate reimbursement, high costs, and limited access to centers or providers who can perform the tests.

Evidence suggests that when a screening recommendation comes directly from the clinician, compliance with colorectal cancer screening can be quite high (2;3;10;11;13). As indicated earlier, colorectal cancer is a highly curable disease when detected early. When diagnosed at an early stage, the five-year relative survival is 90%; yet only 37% of incident cases are diagnosed while still localized (2;13;14) and disparities among racial and ethnic minorities continue to be of concern. To alleviate this public health burden, a commitment to preventive screening among healthcare professionals is necessary. Of primary importance is the fact that clinicians recommend at least one of the appropriate screening options for all eligible patients; the role of the healthcare provider in recommending and conducting preventive screening is a strong predictor of preventive service use (2;3;10-12). At this time, economic and healthcare system disincentives to screening are impinging on the choices available to physicians and patients. However, as familiarity and screening skills grow in the broader medical community, and as insurance and cost obstacles are removed, a greater range of options will be made

available (2). To achieve this requires commitment and collaboration among healthcare providers, insurance companies, and regulatory agencies.

In addition, barriers to screening (e.g., lack of knowledge or awareness, accessibility, language, and cultural sensitivity) need to be addressed in order to make awareness of colorectal cancer and screening opportunities as common as awareness of mammography for breast cancer and PSA for prostate cancer. The most effective modalities appear to be simple, straightforward patient education materials that include brief, hopeful messages about the purpose of screening and its benefits (11;15). Access to screening, clinician recommendations, and education can be effectively combined for favorable impact on screening rates to reduce the debilitating effects of colorectal cancer on our communities.

Clearly, one of the most important priorities for action is to improve public awareness about colorectal cancer as a preventable and curable cancer, about the benefits of colorectal cancer screening, and about the specifics of screening options. Efforts must focus on targeting and reaching multiple

audiences – including those at increased risk, minorities, and other underserved audiences – with messages that encourage specific behavior change. Identifying these audiences and designing effective messages will require a strong research foundation. Collecting data about the public’s knowledge, attitudes, and behaviors concerning colorectal cancer will be critical for developing effective communications with the public in general as well as with specific target audiences. In addition to proactive public awareness efforts, professional awareness strategies will be critical in encouraging providers to discuss colorectal cancer and the benefits of screening with their patients, as well as increasing the number of providers who are themselves screened.

Education and awareness for the public, for the payers, as well as for healthcare professionals, must be employed to open and facilitate dialogue between patients and their healthcare providers in order to increase the usage of colorectal cancer screening tests and to reduce the burden of disease among New Jersey residents. Outreach programs must be developed to eliminate the personal, social, and economic barriers to colorectal cancer screening.

#### **GOAL CO-1:**

**To raise awareness about colorectal cancer for all residents of New Jersey of at least high school age by 2006, with regard to effective measures available for prevention, detection, and treatment to improve the quality of life and survival rates for those diagnosed.**

##### **Objective CO-1.1:**

To target specific educational efforts for subpopulations, including but not limited to, lower socioeconomic status (SES) and high-risk groups, in order to increase awareness of colorectal cancer.

**Strategies:**

- (CO-1.1.1) Review the content of the curriculum the New Jersey Department of Education is developing as supported by Title 18A:40-32, Cancer Awareness Week and Title 18A:40-33, Cancer Awareness Program for School-aged Children, as it relates to colorectal cancer.
- (CO-1.1.2) Provide recommendations to the Department of Education for curriculum development for high school age students, specific to colorectal cancer, which would be included with the general cancer education program.

**Objective CO-1.2:**

To increase the knowledge and change the behaviors of women and men with regard to the importance of colorectal cancer screening and the need to request it.

**Strategies:**

- (CO-1.2.1) Assess knowledge of colorectal cancer among target populations by conducting qualitative research of New Jersey residents.
- (CO-1.2.2) Identify targeted educational interventions to reduce gaps in awareness and behaviors around colorectal cancer screening among men and women 50 years of age and older residing in New Jersey.
- (CO-1.2.3) Develop educational interventions for widespread dissemination of messages about colorectal cancer through multi-faceted delivery mechanisms.
- (CO-1.2.4) Partner with NJCEED to educate and change behaviors of target populations regarding measures available for prevention, detection, and treatment of colorectal cancer.

**Objective CO-1.3:**

To increase the knowledge and change the behaviors of healthcare providers with regard to the importance of colorectal cancer screening and the need for patient education.

**Strategies:**

- (CO-1.3.1) Assess the knowledge, attitudes, and practices of healthcare providers regarding colorectal cancer screening through a statewide survey.
- (CO-1.3.2) Recommend healthcare professional societies educate their members based on identified gaps regarding screening for colorectal cancer.
- (CO-1.3.3) Collaborate with insurers to provide appropriate patient educational materials regarding colorectal cancer screening.

**TREATMENT**

Effective treatment for colorectal cancer at any stage is available and leads to improved survival and/or quality of life. Disparities in treatment and their causes need to be identified so remedies can be devised (16). Outcomes of New Jersey residents with colorectal cancer can be improved by ensuring that high-quality care is available to all New Jersey residents with colorectal cancer. The Colorectal Cancer Workgroup proposes that high-quality colorectal cancer treatment in New Jersey be improved in two ways: (1) by accrediting cancer programs using the American College of Surgeons (ACoS) Commission on Cancer guidelines and (2) by increasing the number of patients enrolled in clinical trials.

Meeting the ACoS Commission on Cancer criteria for an approved cancer program will allow centers to demonstrate their expertise in treating colorectal cancer, help identify disparities in treatment, and facilitate improvement in the care of persons with colorectal cancer. The ACoS Commission on Cancer is dedicated to establishing standards for cancer programs and evaluating and accrediting programs according to those standards. Each approved program provides all patients with a full range of diagnostic, treatment, and supportive services either on site at the facility or by referral. Cancer

programs must improve the quality of patient care by implementing multidisciplinary cancer programs that cover prevention, early diagnosis, pretreatment evaluation, staging, optimal treatment, rehabilitation, surveillance, psychosocial support, and end-of-life care (17). The ACoS collaborates with many different organizations to assure that high-quality prognostic standards are used for cancer management (18).

No published studies have evaluated the effectiveness of ACoS “Approved Cancer Programs” as compared to programs in hospitals whose cancer programs are not approved. However, no other entity exists that provides an extensive set of guidelines against which centers of excellence can be gauged. Nevertheless, 1,400 U.S. cancer programs are accredited by ACoS, and nearly 82% of newly diagnosed patients with cancer are treated in programs accredited by the Commission on Cancer. According to the American College of Surgeons, in 2002, New Jersey has 53 institutions already providing patients with ACoS-approved programs.

One method employed by ACoS to improve patient care is through maintaining the National Cancer Data Base (NCDB), the empirical data collection arm of the ACoS Commission on Cancer supported by the American Cancer Society. The NCDB



collects information about cancer patients through hospital-based cancer registries throughout the U.S. Data are aggregated and reported back to participating hospitals to allow individual facilities to evaluate local patient care practices and outcomes (19). The NCDB has also promoted recognition of important trends, such as the utility of adjuvant therapy for Stage III colon cancer (20).

In addition to increasing the number of ACoS-approved programs, high-quality treatment for colorectal cancer in New Jersey can be promoted through support of clinical trials. Clinical trials are the major avenue for discovering, developing, and evaluating new therapies. However, only about 3% of all adult cancer patients participate in clinical trials. It is important to increase physician and patient awareness of, and participation in, clinical trials if we are to test new treatments more rapidly, find more effective treatments, and broaden the options available to patients (21). New Jersey residents with colorectal cancer should have information about and access to clinical trials.

In 1999, members of the New Jersey Association of Health Plans, which represents the state's nine largest health insurers, agreed to voluntarily cover the routine healthcare costs of any of their members enrolled in a Phase I, II, and III approved cancer clinical trial. In addition, the year 2000 Medicaid contract includes this service, and payment has been authorized for routine costs of clinical trials under Medicare. However, this mandate is not carried over to all insurers, although all companies offering coverage in New Jersey have been invited to participate in the agreement. Patients should contact their insurer prior to entering a clinical trial to obtain specific information about covered benefits (22).

The Colorectal Cancer Workgroup proposes that participation in clinical trials can be increased in New Jersey if awareness is heightened in the public and among professionals. Additionally, insurance coverage of treatment through clinical trials could be improved by increasing the number of insurance companies offering to cover clinical trial participation.

## **GOAL CO-2:**

**To ensure that all those with colorectal cancer receive care from healthcare providers and hospitals with demonstrated proficiency in treatment of colorectal cancer.**

### **Objective CO-2.1:**

To ensure that hospitals that treat cancer patients in New Jersey will have an American College of Surgeons approved cancer program by 2005.

**Strategy:**

- (CO-2.1.1) Recommend that the New Jersey Department of Health and Senior Services develop licensing regulations that mandate American College of Surgeons Commission on Cancer-approved cancer programs in all New Jersey acute care facilities.

**GOAL CO-3:**

**To increase the participation of persons with colorectal cancer in clinical trials.**

**Objective CO-3.1 :**

To increase awareness of the availability and importance of clinical trials among New Jersey residents with colorectal cancer and their healthcare providers.

**Strategy:**

- (CO-3.1.1) Develop an educational program to promote participation in and enhance public visibility and understanding of important clinical trials for colorectal cancer.

**Objective CO-3.2 :**

To ensure access to participation in clinical trials for residents with colorectal cancer.

**Strategy:**

- (CO-3.2.1) Expand the number of insurers who offer clinical trial participation.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: CO-1.2.4; CO-2.1.1

New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection (NJCEED): CO-1.1.1; CO-1.1.2; CO-1.2.2; CO-1.2.3; CO-1.2.4; CO-1.3.2

## COLORECTAL

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Raise awareness	1.1: Target specific educational efforts for subpopulations	CO-1.1.1						
		CO-1.1.2						
	1.2: Increase knowledge and change behaviors of the public	CO-1.2.1						
		CO-1.2.2						
		CO-1.2.3						
		CO-1.2.4						
	1.3: Increase knowledge and change behaviors of healthcare providers	CO-1.3.1						
		CO-1.3.2						
		CO-1.3.3						
2: Ensure treatment by healthcare providers with demonstrated proficiency	2.1: Ensure ACoS-approved cancer programs in hospitals	CO-2.1.1						
3: Increase participation in clinical trials	3.1: Increase awareness of clinical trials	CO-3.1.1						
	3.2: Ensure access to participation in clinical trials	CO-3.2.1						

Target Completion Date

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## CHAPTER 9. Lung Cancer

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## LUNG CANCER

### IMPORTANCE OF LUNG CANCER FOR CANCER PREVENTION AND CONTROL

Lung cancer is the leading cause of cancer death among U.S. men and has been the leading cause of death among women since 1987, when it surpassed breast cancer (1;2). Smoking is by far the leading risk factor for lung cancer, and the most effective way to reduce lung cancer morbidity and mortality is to reduce tobacco use. Tobacco smoking is responsible for 87% (almost 9 out of 10) cases of lung cancer (1).

Smoking is the single most preventable cause of death and disease. More Americans die from smoking each year than from AIDS, alcohol, other drugs, motor vehicle accidents, homicide, and suicide combined. Smoking will cost the nation \$157 billion and 440,000 premature deaths each year (3). Entering tobacco dependence treatment is among the most cost-effective health measures second only to immunization. Overall, smoking is responsible for more than 13,000 deaths annually in New Jersey alone. Annual tobacco-related healthcare costs in New Jersey are \$2.6 billion (4).

Early detection is necessary if we are to decrease mortality from lung cancer. Currently, however, there is no recommended screening or early detection method for lung cancer. New treatment approaches and early treatment for lung cancer are needed to reduce mortality, increase survival, and improve quality of life. When appropriate, physicians in New Jersey should promote participation in

clinical trials for their patients at high risk for lung cancer and for those who have been diagnosed with lung cancer.

Nationally, unexplained cancer-related health disparities remain among population subgroups (e.g., blacks and individuals with low socioeconomic status have the highest overall rates for both incidence and mortality) (5). New Jersey must also address existing lung cancer morbidity and mortality disparities by race and gender, especially for black men, through funded research.

### LUNG CANCER IN NEW JERSEY

**Incidence.** Lung cancer is the second most common cancer in the U.S. and in New Jersey, accounting for about 13% of all cancer diagnoses. Reflecting the national trend of decreasing lung cancer incidence among men, New Jersey has seen a decreasing trend in incidence since late 1980s. Female lung cancer incidence rates have been rising in New Jersey and the U.S. While lung cancer incidence rates for white females in New Jersey are slightly higher than those among black females (55.7 versus 49.8 per 100,000\*\* in 2000\*), the incidence rates for black males in New Jersey are substantially higher than for white males (106.3 versus 85.3 per 100,000\*\* in 2000\*) (Figure 1). In 2002 the American Cancer Society estimates that only 4,900 new lung cancer cases will be diagnosed in New Jersey compared to about 6,200 diagnosed in New Jersey in 1998, again reflecting the national trend in decreasing lung cancer incidence (1).

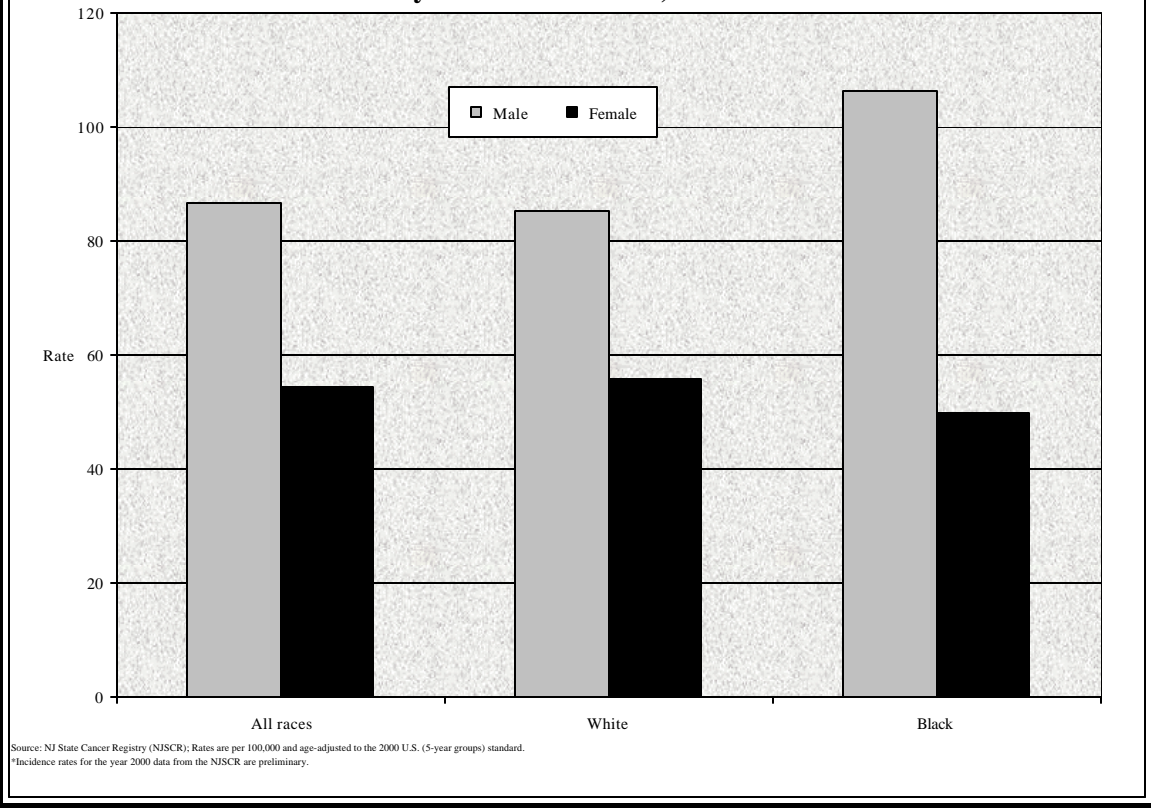
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\*Incidence rates for the year 2000 data from the New Jersey State Cancer Registry are preliminary.

\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.



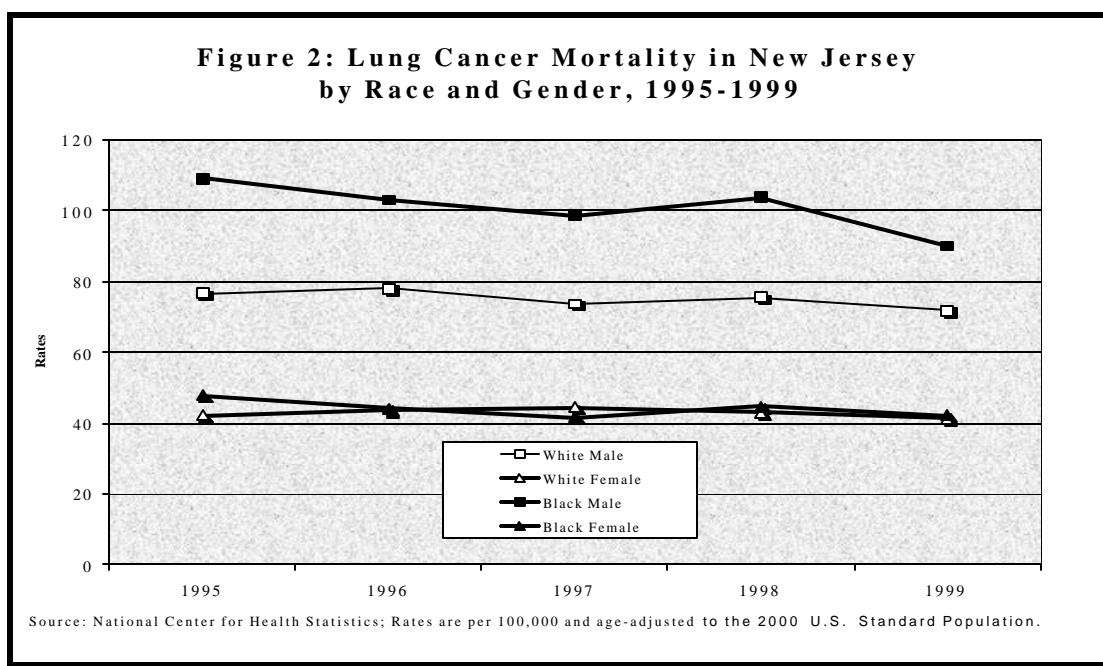
**Figure 1: Lung Cancer Incidence Rates in New Jersey  
by Race and Gender, 2000\***



**Mortality.** Lung cancer is the most common cause of Lung cancer is the most common cause of cancer death in the U.S. and in New Jersey, accounting for about 28% of all cancer deaths. U.S. mortality rates from the National Center for Health Statistics revealed that lung cancer among men (all races combined) has decreased from 84.5 per 100,000\*\* in 1995 to 77.2 per 100,000\*\* in 1999. For New Jersey females, mortality rates during the same time period remained

relatively stable. For the years 1995 through 1999, black males in New Jersey have the highest mortality rate, followed by white males. Both white and black females in New Jersey during the same years were similar (Figure 2). The American Cancer Society estimates that, in 2002, 4,500 new lung cancer deaths will occur in New Jersey compared to about 4,800 deaths that occurred in 1998, representing a very small change (1).

\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.



Below is the Healthy New Jersey 2010 goal relating to lung cancer.

**Healthy New Jersey Goal: Reduce the age-adjusted death rate from lung cancer per 100,000 standard population to target below, by 2010.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	35.2	28.5	-19.0	25.0	-29.0
White age-adjusted	35.0	28.5	-18.6	25.0	-28.6
Black age-adjusted	43.8	31.6	-27.9	25.0	-42.9
Asian/Pacific Islander age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#
Male age-adjusted	46.4	29.0	-37.5	25.0	-46.1
Female age-adjusted	26.6	25.5	-4.1	25.0	-6.0
Persons 65+	322.1	296.9	-7.8	274.7	-14.7

<sup>#</sup>Data are statistically unreliable.  
Source: Healthy New Jersey 2010

In support of the Healthy New Jersey 2010 goal for lung cancer, the recommendations of the Lung Cancer Workgroup are summarized below for the following four topic areas in priority order:

- Tobacco Control
- Provider Education
- Early Detection and Treatment
- Research

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## GOALS, OBJECTIVES AND STRATEGIES

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### TOBACCO CONTROL

The major intervention in the prevention of lung cancer is tobacco control. The most effective approach is to enact public policies that reduce tobacco use. Proven strategies include increasing tobacco taxes, making tobacco dependence resources available, and restricting tobacco use in public places (6;7). Tobacco control programs in New Jersey should build on an existing activity, the New Jersey Comprehensive Tobacco Control Program (8-11).

Other issues surrounding Tobacco Control include:

- Targeting racial, gender, and cultural disparities
- Reducing exposure to Environmental Tobacco Smoke (ETS)
- Educating healthcare providers and insurers

- Access to and funding for smoking cessation
- Promoting public information/support
- Active advocacy for smoke-free environments
- Countermarketing to tobacco industry marketing and promotional activities (8)

For each of these issues, the Comprehensive Tobacco Control Program has identified specific problems and specific strategies for overcoming them. For example, relating to provider education, the literature clearly shows that, although we now have clear guidelines for the treatment of tobacco dependence, the implementation and execution of these by providers has been less than optimal. The next step is to look at implementation barriers and facilitate provider actions to achieve the desired practices.

#### GOAL LU-1:

**To adopt the goals already formulated by the New Jersey Comprehensive Tobacco Control Program, namely to:**

- **Decrease the acceptability of tobacco use among all populations**
- **Decrease the initiation of tobacco use by youth under 18 years of age and youth 18 to 24 years of age**
- **Increase the number of youth and adult tobacco users who initiate treatment**
- **Decrease exposure to environmental tobacco smoke**
- **Reduce disparities related to tobacco use and its effects among different population groups (10)**

#### Objective LU-1.1:

To support the long-term goals of the New Jersey Comprehensive Tobacco Control Program and its comprehensive components by increasing funding to the levels recommended by the Centers for Disease Control and Prevention (CDC).

**Strategies:**

- (LU-1.1.1) Broaden the number and scope of advocates for tobacco control by identifying new advocates and advocacy groups that will advocate for tobacco control.
- (LU-1.1.2) Support an increase in the state tobacco excise tax.
- (LU-1.1.3) Support giving local governments authority to regulate public smoking by repealing existing state statutes that pre-empt such authority.
- (LU-1.1.4) Increase the awareness of state-sponsored tobacco treatment resources in communities.

**PROVIDER EDUCATION**

One of the most important advancements in tobacco dependence treatment has been the recent update of the Public Health Service Guidelines for Treating Tobacco Use and Dependence (henceforth referred to as the PHS Guidelines) (12). Now that these guidelines exist, the next challenge is to persuade healthcare providers to implement the recommendations in their respective practices. The guidelines provide clinicians with excellent strategies to help their patients abstain from tobacco. However, the guidelines are rendered useless if providers are unaware of them and are unable to execute them effectively.

The importance of enlisting healthcare providers in tobacco-related treatment has been demonstrated in several ways. It is reported that 70% of smokers visit a healthcare provider each year (13), and smokers visit their doctor on average six times per year (14), thus allowing for considerable patient/provider contact. Despite the commonly accepted knowledge of the adverse health effects of smoking, a significant number of smokers are still unclear of the dangers they are risking (15). Patients view their healthcare provider as an

important and credible source of medical information and, therefore, providers must be up to date on tobacco-related issues. Patients report that a strong quit message from a provider is a very important motivating factor in the quitting process (16). Reviews show that clinician advice to quit alone can cause a 2.5% increase in cessation rates (17). Although this percentage may seem small, it is far from negligible when considered in light of the 1.2 million smokers in the state. Moreover, simple advice to quit has a cumulative effect, and the patient can interpret omitting the advice as a rationalization that quitting is not as important as some say it is and that the clinician does not care. Providers also have the opportunity to intervene in circumstances beyond the direct patient's habit. This would include pediatricians addressing environmental tobacco smoke in the household of smokers, and obstetricians addressing smoking during pregnancy and the fetal effects.

There is good evidence that healthcare providers are not fully aware of recommendations published by experts in the tobacco arena. The National Cancer Institute's "4 A's: Ask, Advise, Assist, Arrange" Strategy for physician counseling was published in 1994, and in 1996, the Agency for Health Care Policy and Research (now the Agency for Healthcare Research and

Quality) released evidence-based clinical practice guidelines for physician practices. Despite these clear recommendations, studies have shown that several years later these basic recommendations are not universally executed. In one study examining patient report, 51% of smokers were “asked” about their smoking, 45% were “advised” to quit, 15% were offered help (“assisted”), and only 3% had follow-up “arranged” (18). In another study looking at physician practices in the 1990s, smoking status (ask) was identified in 67% of visits, counseling of smokers occurred in only 21% of visits, and prescription of nicotine replacement therapy occurred in only 1.3% of visits (19). In New Jersey, two out of three adults and one-half of youth reported being asked their smoking status by their clinician, and more than one-half of adult smokers were advised to quit (8). Nearly one-half of current smokers were not given specific advice to stop. Providers are not meeting the recommended levels of tobacco treatment. Now that we have another updated, evidence-based guideline, we need to improve providers’ utilization of the guidelines in order to prevent lost opportunities.

The PHS Guidelines also make clear that although brief interventions by clinicians can have an impact, more intense interventions have even greater effect. Interventions have been shown to operate in a dose-response fashion; the more intense the intervention and

the more resources utilized the higher the rates of success (12). This effect applies to any smoker willing to participate, not simply those unable to achieve abstinence on their own or with the help of their primary care provider. Luckily, excellent resources exist in New Jersey for specialized treatment. These include the Quitline, Quitnet, and Quitcenter. Unfortunately, these specialized resources suffer the same drawbacks as the Guidelines; if providers are unaware of them, they cannot refer smokers to them. Therefore, for all of the reasons outlined above, a concerted effort must be made to inform providers of the resources available for specialty referral. We must first establish how providers can best be reached and informed, and then interventions must be implemented to disseminate the information. Only in this way can the state’s efforts at reducing tobacco use be fully realized.

In terms of reducing barriers for tobacco dependence treatment, Healthy People 2010 includes an objective to “increase insurance coverage of evidence-based treatment for nicotine dependency” (20). In order for this objective to be met, a strong advocacy effort must be undertaken to convince third-party insurers that efforts to increase cessation are cost effective in both the short and the long term. If reimbursement is increased to the Healthy People 2010 goals, a major barrier to tobacco dependence treatment as reported by providers will be reduced.

#### **GOAL LU-2:**

**To increase the proportion of providers in New Jersey who properly and effectively implement the Public Health Service Guidelines regarding tobacco dependency treatment.**

**Objective LU-2.1:**

To increase provider knowledge regarding standard of care for tobacco dependency treatment in the State of New Jersey.

**Strategies:**

- (LU-2.1.1) Support the assessment of providers' current knowledge regarding Public Health Service guidelines for tobacco dependency treatment via a provider survey.
- (LU-2.1.2) Support the development and/or promotion of educational programs to increase the awareness of Public Health Service guidelines for tobacco dependency treatment. These interventions will target stakeholders of provider organizations.

**Objective LU-2.2:**

To increase provider knowledge regarding available resources for tobacco dependency treatment in New Jersey (Quitline, Quitnet, and Quitcenters).

**Strategies:**

- (LU-2.2.1) Support the assessment of providers' current awareness of New Jersey's efforts for tobacco control via a statewide providers' survey.
- (LU-2.2.2) Support promotional programs to increase the awareness of tobacco dependency treatment in New Jersey (Quitline, Quitnet, and Quitcenters).

**Objective LU-2.3:**

To reduce the barriers for insurance providers in implementing the Public Health Service guidelines for tobacco dependency treatment.

**Strategy:**

- (LU-2.3.1) Advocate for third-party payer reimbursement of tobacco dependency treatment.

## **EARLY DETECTION AND TREATMENT**

According to 2002 estimates, lung cancer remains the number one cause of cancer-related death in men and women in the nation. The overall long-term (five-year) survival for lung cancer only increased from 12% in 1974 to 15% in 1997 (21). Despite poor survival in general, five-year survival for resected Stage I lung cancers can be as high as 40% to 70%, although only 15% of lung cancers are localized at the time of diagnosis. Advanced lung cancer accounts for more cancer deaths in the U.S. than the combination of the next three most common causes of cancer death: colorectal, breast, and prostate cancers. However, lung cancer is the only one of these cancers for which there are no screening recommendations (22).

The goal of a screening program is to detect cancers at an early stage when they are small and asymptomatic and when treatment leads to a higher cure rate (23). Any significant change in the stage distribution at presentation offers the possibility of a profound impact on cancer death rates, given the prevalence of lung cancer. During the 1970s, the National Cancer Institute (NCI) sponsored the Cooperative Early Lung Cancer Detection program, and more recent 20-year follow-up data from the Mayo Lung Project confirmed that early detection of lung cancer with chest x-ray at frequent intervals does not decrease mortality from lung cancer. Although there was a greater surgical resectability rate in the screened patients and survival time was increased, there was no effect on overall mortality rates. As a result of these and similar trials, no national recommendations for lung cancer screening were made (24;25).

Recent technological advances and development of new tools for screening have led to renewed trials of methods for detection of early stage lung cancers. The most promising of these is the low radiation dose spiral

computer topography (CT) scan (26). Low dose CT requires less than 20 seconds of scanning time, does not require intravenous contrast, and is much less expensive than a standard chest CT. The cost is only slightly higher than the cost of a chest radiograph, and the radiation exposure is about equal (27).

Recent trials in Japan and in the United States, the Early Lung Cancer Action Project (ELCAP), compared low dose spiral CT with chest x-ray (CXR) and found that the CT was able to detect early stage tumors six times more often (27). These promising results have become the basis for broader randomized trials using low dose CT scanning with lung cancer mortality as an end point. Before spiral CT is accepted into medical practice, it is critical to determine whether this modality will reduce lung cancer mortality. Toward this goal, the National Cancer Institute is implementing the Lung Screening Study (24).

The second issue identified by the Lung Cancer Workgroup was detection and treatment that would ensure adequate access to state-of-the-art and investigational therapy for all New Jerseyans. This issue also included a compassionate outreach effort through psychosocial support, education, and other modalities to promote improved quality of life for those diagnosed with lung cancer and their caregivers. There is a dire need to make a clinical impact on lung cancer through new strategies for treatment of established disease, earlier treatment intervention and prevention, as well as to ensure that best practices for the management of lung cancer are adopted and appropriately applied across the state. Because of the need to make therapeutic progress against this disease, it is important that models of care optimize the delivery of best-known clinical practice. It is also important to determine the effects of these models on the processes and outcomes of care and on accrual of patients to clinical trials (28).



**GOAL LU-3:**

**To increase the detection of lung cancer at earlier stages.**

**Objective LU-3.1:**

To monitor low dose spiral CT as an effective screening method to decrease lung cancer mortality.

**Strategies:**

- (LU-3.1.1) Monitor and support the NCI's progress in defining the value of spiral CT and other effective methods as a recommended screening method for lung cancer.
- (LU-3.1.2) Educate New Jersey healthcare providers about state-of-the-art lung cancer screening, especially if a national lung cancer screening recommendation as defined by a large controlled randomized study is issued.
- (LU-3.1.3) Promote efforts to have the screening tests covered by health insurers and third-party payers.
- (LU-3.1.4) Promote the State of New Jersey's participation in a national trial for determining the effectiveness of spiral CT.

**GOAL LU-4:**

**To increase survival, decrease mortality, and improve quality of life through early detection and treatment of lung cancer.**

**Objective LU-4.1:**

To develop Centers of Excellence throughout the state for early detection and treatment of lung cancer.

**Strategy:**

- (LU-4.1.1) Advocate for Centers of Excellence throughout the state for early detection and treatment of lung cancer.

## RESEARCH

**L**ung cancer is the leading cause of cancer death in the United States. Its major cause is cigarette smoking. Lung cancer is usually detected at the late stage, making treatment more difficult. Therefore, tobacco control and early detection are the two most important strategies for the reduction of lung cancer incidence and mortality. However, further research is needed to develop more effective measures for tobacco control and early detection.

In 2000 the NCI estimates that it will spend only \$950 for research per lung cancer death compared to \$8,860 per breast cancer death, \$3,667 per prostate cancer death, and \$3,192 per colon cancer death (29). The need for increased funding for lung cancer research is apparent.

As discussed previously, many early detection methods are still in the research stage. We should encourage New Jersey residents to participate in early lung cancer detection trials. Recent advances in cancer biology suggest the potential for developing molecular markers, such as P16 gene hypermethylation and p53 gene mutation, for the detection of early stages of lung cancer or even precancerous lesions. Research in this area is highly promising and should be encouraged in New Jersey.

### **GOAL LU-5:**

**To increase accrual and broaden access to lung cancer clinical early detection and treatment trails for patients and physicians in New Jersey.**

#### **Objective LU-5.1:**

To support the National Cancer Institute's Clinical Trial Implementation Committee Goals for Clinical Trials for lung cancer.

The percentage of adults and children with cancer who participated in NCI Cooperative Group trials from 1991-1994 was 2.5% (30). A requirement for every American College of Surgeons-certified oncology program is that 2% of the patient population be enrolled in clinical trials (31). These numbers should be increased, especially concerning lung cancer early detection trials.

Of those with lung cancer, a majority is diagnosed in late-stage disease. Currently, the goal of standard therapy for Stage IV lung cancer is palliation of symptoms and prolongation of survival, not cure. Enrolling patients in clinical protocols to trial new treatments and investigational agents may lead to improved outcomes and perhaps decreased mortality.

Actions that should be taken in New Jersey with regard to lung cancer research include:

- Lobby for increased funding for lung cancer research
- Promote research on effective means for tobacco control
- Promote research on effective means for detecting lung cancer at early stages and precancerous lesions
- Promote research on the treatment of lung cancers at early and later stages

**Strategy:**

- (LU-5.1.1) Develop educational programs to promote participation and enhance public visibility and understanding of important lung cancer clinical trials.

**GOAL LU-6:**

**To increase research activities for establishing reliable methods for the early detection of lung cancer and precancerous lesions.**

**Objective LU-6.1:**

To promote research on early detection of lung cancer and precancerous lesions.

**Strategies:**

- (LU-6.1.1) Assess the current numbers of studies and the total in the area of early detection of lung cancer and precancerous lesions.
- (LU-6.1.2) Support existing research projects and fund additional pilot projects for early detection of lung cancer and precancerous lesions.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

Cancer Institute of New Jersey: LU-3.1.1; LU-3.1.4; LU-4.1.1; LU-5.1.1; LU-6.1.1; LU-6.1.2

Communities Against Tobacco Coalitions: LU-1.1.1; LU-1.1.3; LU-1.1.4

New Jersey Breathes Coalition: LU-1.1.1; LU-1.1.2; LU-1.1.4

New Jersey Department of Health and Senior Services, Division of Addiction Services: LU-1.1.1; LU-1.1.4; LU-2.1.1; LU-2.2.1; LU-2.2.1; LU-2.2.2

New Jersey QuitCenters: LU-1.1.4

University of Medicine and Dentistry of New Jersey/School of Public Health, Tobacco Dependence Treatment Program: LU-2.1.1; LU-2.1.1; LU-2.2.1; LU-2.2.2; LU-3.1.2; LU-3.1.3

## LUNG

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Adopt goals of the Comprehensive Tobacco Control Program (CTSP)	1.1: Support long-term goals of CTSP	LU-1.1.1						
		LU-1.1.2						
		LU-1.1.3						
		LU-1.1.4						
2: Increase provider utilization of tobacco dependency treatment guidelines	2.1: Increase provider knowledge of standards of care	LU-2.1.1						
		LU-2.1.2						
	2.2: Increase provider knowledge of resources	LU-2.2.1						
		LU-2.2.2						
3: Increase earlier stage lung cancer detection	3.1: Monitor effective screening methods	LU-2.3.1						
		LU-3.1.1						
		LU-3.1.2						
		LU-3.1.3						
4: Improve quality of life through early detection and treatment	4.1: Develop Centers of Excellence	LU-3.1.4						
		LU-4.1.1						
5: Increase clinical trials	5.1: Support NCI's Clinical Trial Implementation Goals	LU-5.1.1						
6: Increase research activities	6.1: Promote research	LU-6.1.1						
		LU-6.1.2						

Target Completion Date

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## CHAPTER 10. Melanoma

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## MELANOMA

### IMPORTANCE OF MELANOMA FOR CANCER PREVENTION AND CONTROL

Skin cancer is the most common cancer in the United States, affecting some 1 million Americans every year. There are three main types of skin cancer: basal cell, the most prevalent; squamous cell; and malignant melanoma. Basal and squamous cell cancers have an excellent prognosis, but persons with a nonmelanoma skin cancer are at higher risk for developing additional skin cancers (1-3). Melanoma of the skin<sup>§</sup> or cutaneous malignant melanoma, the rarest but most lethal form of skin cancer, is responsible for about three-fourths of all deaths from skin cancer and is, therefore, the focus of this report (1;4). It should be noted that nonmelanoma skin cancers are also important and should not be neglected. Many of the recommendations offered in this report will apply to malignant melanoma of the skin, as well as to nonmelanoma skin cancers and other types of malignant melanoma (e.g., ocular).

Incidence of cutaneous malignant melanoma\* is increasing annually (4) at a rapid pace. In the United States alone, the lifetime risk for developing cutaneous melanoma is approximately 1 in 80 persons, an almost 200% increase in incidence since 1930. Persons born prior to 1930 have experienced the sharpest increases (5). In the U.S., about one-fourth of melanoma patients are diagnosed before age 40 (6). Thus, the years of life lost from cutaneous melanoma are higher than for most other forms of cancer. In 2002, it is estimated that 30,100 new cases of cutaneous malignant melanoma will be diagnosed in males and

23,500 in females (7). Approximately 4,700 men and 2,700 women will die from cutaneous melanoma in 2002 (7). In recent years, melanoma is one of the cancer sites showing the most marked increases nationally (8). The American Cancer Society estimates that, in 2002, melanoma of the skin will be the fifth leading new cancer site in the U.S. for men and the sixth leading new cancer site in the U.S. for women, accounting for 5% and 4% of all cancers, respectively (7).

Exposure to solar ultraviolet radiation (UV light) is well established as a major risk factor for melanoma (9-11). Other risk factors include skin coloring (11;12), geographic location (10;11), sunburn history (9;10;12), and melanocytic nevi (10). Cutaneous melanoma prevention begins with avoidance of exposure to the sun, especially during midday. Those who cannot avoid the sun should limit direct sun exposure using broad-brimmed hats, long-sleeved shirts, pants, sun-resistant fabrics, or sunscreen.

### MELANOMA IN NEW JERSEY

**Incidence.** New Jersey cutaneous melanoma incidence rates reflect the national trend of increasing incidence (8). The stage at which melanoma is being diagnosed in New Jersey is improving. In 2000\*, 88% of melanomas were diagnosed in the early stages (in situ and local) compared to 70% in 1995. Data from the New Jersey State Cancer Registry\* reveal that the incidence rate of melanoma in New Jersey men (all races combined) increased consistently from 1979, peaking at 21.6 per 100,000\*\* in 1997 and decreasing to 18.5 in

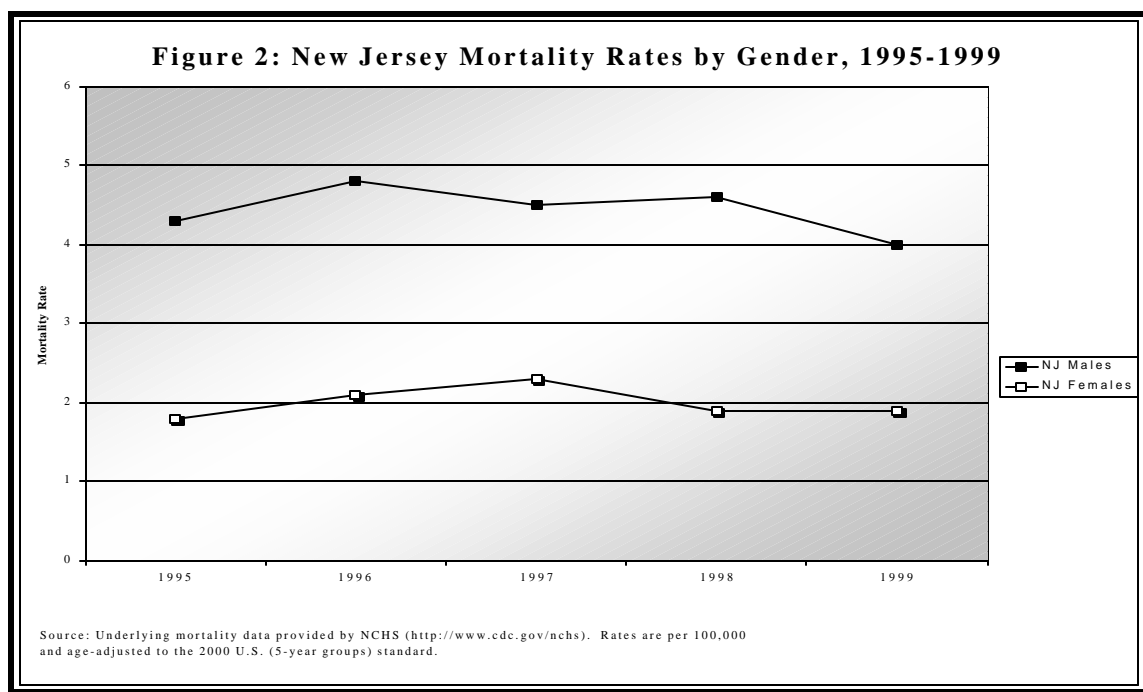
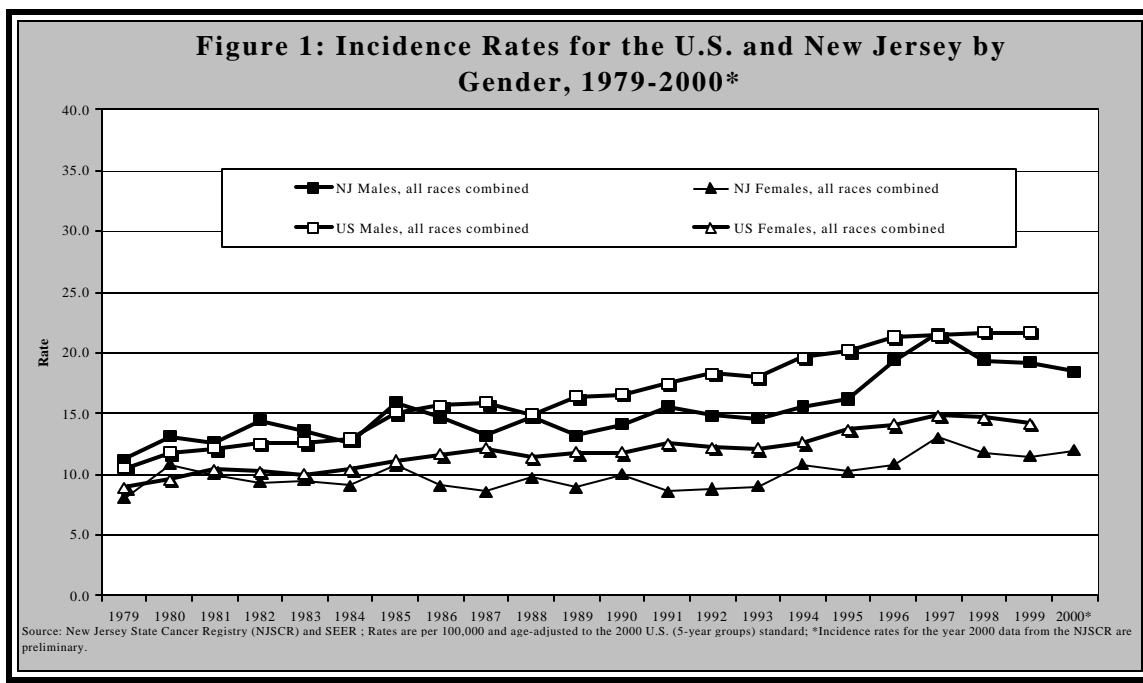
\*Incidence rates for the year 2000 data from the New Jersey State Cancer Registry are preliminary.

\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

§The New Jersey State Cancer Registry data reflect cutaneous malignant melanoma of the skin and do not include basal and squamous cell skin cancers. The American Cancer Society data reflect melanoma of the skin and do not include basal and squamous cell skin cancers.

2000\* (Figure 1). The American Cancer Society estimates that, in 2002, 1,800 new melanoma cases will be diagnosed in New Jersey (7). Melanoma incidence rates

increase as age increases. The highest rates of melanoma in New Jersey are in males, age 80-84 (incidence rate = 99.8 per 100,000\*\* for the years 1995-2000\* combined).



\*Incidence rates for the year 2000 data from the New Jersey State Cancer Registry are preliminary.

\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

**Mortality.** Data from the National Center for Health Statistics reveal that cutaneous melanoma mortality rates for New Jersey males and females remained relatively stable between 1995 and 1999 (4.3 in 1995 versus 4.0 per 100,000\*\* in 1999 for males and 1.8 in 1995 versus 1.9 per 100,000\*\* in 1999 for females. This is consistent with rates for the U.S. (Figure 2).

**Behavioral Risk Factor Surveillance System Data.** According to the stratified estimates from the 1999 New Jersey Behavioral Risk Factor Surveillance System, more males than females (30.6 % compared to 21.7%) answered 'yes' to the question 'Did you have a sunburn in the past 12 months?'

for all ages combined. When broken down by age, the subgroup of 18- to 34-year-olds had the highest percentage of sunburns within the past year (40.2 %).

Cutaneous melanoma is a serious threat in New Jersey in particular, where melanoma incidence rates are the eighth highest in the nation. In New Jersey, approximately 1,800 melanoma cases are estimated to be diagnosed in 2002 (7). New Jersey has a very active coastal community where tourists visit the beaches and other outdoor attractions every summer. Many opportunities exist to prevent cutaneous malignant melanoma through these recreational activities and facilities.

Below is the Healthy New Jersey 2010 goal related to melanoma.

**Healthy New Jersey 2010 Goal: Reduce the age-adjusted incidence rate of invasive melanoma per 100,000 to 7.0 for the total population, 8.0 for whites, and 0.3 for blacks.**

**Table 1. Baseline data and projected target rates to reduce the rate of invasive melanoma.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	12.4	7.0	-43.5	6.2	-50.0
White age-adjusted	14.5	8.0	-44.8	7.3	-49.7
Black age-adjusted	0.8	0.3	-62.5	0.2	-75.0
Asian/Pacific Islander Age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#

Source: Healthy New Jersey 2010

#Data are statistically unreliable

In support of the Healthy New Jersey 2010 goal for melanoma cancer, the recommendations of the Melanoma Workgroup are summarized below for the following three topic areas in priority order:

- Awareness
- Education
- Treatment

\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. population standard.

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## GOALS, OBJECTIVES AND STRATEGIES

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### AWARENESS

As demonstrated earlier in this chapter, protection from UV rays is the easiest way to eliminate the most common risk factor for cutaneous melanoma. However, according to the 1998 National Health Interview Survey, only 27% of adults sought out shade, only 23% wore protective clothing when exposed to sunlight, and only 30% routinely used sunscreen (14). These low percentages clearly demonstrate the need to make the public more aware of UV exposure as a risk factor for cutaneous melanoma.

The Centers for Disease Control and Prevention (CDC) is developing several population-based interventions to prevent skin cancer. The national campaign “Choose Your Cover” increases awareness about skin cancer, while also influencing social norms regarding sun protection and tanned skin. Additionally, the CDC has convened the National Council on Skin Cancer Prevention; the Federal Council on Skin Cancer Prevention; and other public awareness campaigns such as Pool Cool; Sunwise Stampede; The National Coalition for Skin Cancer Prevention in Health, Physical Education, Recreation and Youth Sports; and the Coalition for Skin Cancer Prevention in Maryland. (For additional information on these programs, please visit the CDC website: [www.cdc.gov/cancer/nscepep/skin.htm](http://www.cdc.gov/cancer/nscepep/skin.htm).)

The most common public awareness message is that of the “ABCD’s of Melanoma (15),” which describes suspicious lesions as those that are **A**symmetrical, have an irregular **B**order, have **C**olor variegation, and have a **D**iameter greater than 6 millimeters.

Awareness campaigns are most prevalent in the form of educational materials for display in dermatologist offices. However, this type of campaign only targets those who have already taken the initiative to visit the dermatologist; those who do not visit the dermatologist or a primary care physician are being missed. Although the basic message of the program is correct, people are only encouraged to look for advanced signs of disease, not early warning signs.

Despite these national efforts, New Jersey is still estimated to rank 8<sup>th</sup> in the nation for cutaneous melanoma incidence for 2002 (7). As stated in the introduction to this chapter, while diagnosis in the early stages is increasing, data from the New Jersey State Cancer Registry show that the diagnosis of cutaneous melanoma in the late stages has remained steady from 1994 through 1998 (8). This presents clear evidence that early detection and screening efforts must be improved.

The fact that melanoma is a life-threatening disease must be communicated effectively to the public and to healthcare professionals in order to increase melanoma diagnoses in the early stages and decrease melanoma diagnoses in the late stages. The Melanoma Workgroup recommends the development of awareness campaigns that target early diagnosis. Awareness issues must be addressed on four levels. First, the public at all age levels must be made aware of the gravity of the disease and the need for preventive measures. Second, patients must be made aware of the treatment regimens that are available immediately after diagnosis. Third, medical professionals must be made aware of state-of-the-art diagnosis and treatment programs, as well as the quality-of-

life issues that accompany these treatments. Fourth, the public and professionals must be aware of the facilities in New Jersey that offer

state-of-the-art diagnosis and treatment for melanoma of the skin.

#### **GOAL ME-1:**

**To decrease the number of melanomas being diagnosed in late stages and increase the percent of melanomas being diagnosed in early stages.**

#### **Objective ME-1.1:**

To promote state-of-the-art diagnosis and treatment for melanoma in facilities that target the citizens of New Jersey.

#### **Strategies:**

- (ME-1.1.1) Develop continuing education programs to educate New Jersey healthcare providers about state-of-the-art early diagnosis and treatment techniques for melanoma.
- (ME-1.1.2) Develop and distribute a resource guide specific to melanoma to promote awareness of New Jersey Centers of Excellence for state-of-the-art diagnosis and treatment. Using this tool, patients will be able to locate providers in their area for melanoma prevention, detection, treatment, and referral.
- (ME-1.1.3) Develop an awareness campaign targeted to New Jersey residents regarding state-of-the-art treatment and diagnosis of melanoma.
- (ME-1.1.4) Encourage New Jersey primary healthcare providers to send their patients to New Jersey Centers of Excellence for melanoma and skin cancer care.

#### **Objective ME-1.2:**

To develop an alliance with businesses and organizations to develop skin cancer media campaigns promoting public awareness and knowledge.

#### **Strategies:**

- (ME-1.2.1) Develop and disseminate educational materials and programs in collaboration with organizations such as the American Cancer Society.

- (ME-1.2.2) Collaborate with pharmaceutical industries that make sunscreen to launch a skin cancer awareness campaign piggybacked on their product marketing.
- (ME-1.2.3) Partner with cosmetic companies and other industries to launch a skin cancer awareness campaign piggybacked on their product marketing.

## EDUCATION

**School-based education.** New Jersey school districts must be committed to the promotion of comprehensive school health education in the form of Kindergarten through 12<sup>th</sup> grade health instruction that is planned, documented, sequential, and age appropriate. It is recognized that classroom instruction is not effective unless coordinated with, and reinforced by, policies and programs within other components of the school health program. According to the American Cancer Society Sun Safe Community Project, school personnel need to work together with community representatives to ensure that the health needs of students are met and that the school health program reflects the interests of both school and community.

Awareness of the increasing rate of melanoma incidence must be presented to school health educators to impress upon them the seriousness of the problem in our state. The incidence rates can be lowered and the behaviors of the student-aged population can be modified with assistance from these school health professionals.

Education on prevention meets one need as evidenced by the rate of incidence statistics for the State of New Jersey. Outcomes resulting from school health education on the prevention, detection, and screening of melanoma will not have immediate impact on the incidence rates but will rather provide a foundation of support for long-term sun-safe programs and policies within the school setting. Sun-safe community promotion can

augment existing sun-safe messages, if present, or encourage the school administration to review existing instruction and policies relating to sun safety.

Schools can promote sun safety through updated policies and by providing environmental support. School policies may address issues such as scheduling outdoor activities before or after those times of day when the sun's rays are most intense and by encouraging all participants in outdoor activities to wear sun-safe clothing, hats, and sunscreen. Providing environmental support by increasing the amount of shade on the school campus is an important way schools can decrease student exposure to the sun. Increasing shade may include planting additional trees in open spaces, erecting temporary and permanent shade structures in such places as lunch areas and playgrounds, and making indoor space available to students for days and/or times when the sun's rays are especially intense.

**Community education.** Strong evidence exists that melanoma is being detected earlier than previously. Many publications have demonstrated a dramatic rise in the proportion of thin melanomas, particularly after educational campaigns. A 600% increase in the diagnosis of in situ melanoma in the United States between 1973 and 1987, although the incidence of invasive melanoma increased by 52% nationally, is additional evidence for the earlier detection of malignant melanoma.

In an ideal world, early detection and excision of premalignant melanoma and thin melanomas would decrease both melanoma incidence and mortality associated with the disease. Berwick et al. has demonstrated that early detection through self-examination could have this effect (16). Berwick's study showed a decrease in the incidence of invasive melanoma associated with self-examination that might be associated with

earlier detection of premalignant skin lesions. Berwick further refers to 3,142 patients analyzed by MacKie, first diagnosed between 1979 and 1993, in a study demonstrating that age-standardized incidence was highest among the most affluent men and women as was five-year disease-free survival, which, in turn, implies that greater access to early detection and medical care reduces the mortality rate of melanoma.

### **GOAL ME-2:**

**To increase the practice of prevention behaviors among youth by instructing students in all New Jersey public school districts on prevention, detection, and screening for melanoma and other skin cancers.**

### **Objective ME-2.1:**

To include in the curriculum of all public schools, and enhance where necessary, instruction on prevention, detection, and screening of melanoma and other skin cancers. This is supported by New Jersey Statutes, Title 18A:40-32, Cancer Awareness Week and 18A:40-33, Cancer Awareness Program for School-aged Children.

### **Strategies:**

- (ME-2.1.1) Train representatives from school districts about melanoma and skin cancer prevention, detection, and screening.
- (ME-2.1.2) Implement incentives for training by providing professional development hours or continuing education credits relating to skin cancer.
- (ME-2.1.3) Partner with the American Cancer Society and other healthcare organizations to train appropriate professionals in school districts on proven skin cancer prevention programs, e.g., Sun Safe Communities.
- (ME-2.1.4) Educate parents at PTO/PTA meetings regarding prevention, detection, and screening for melanoma and other skin cancers.



- (ME-2.1.5) Implement an awareness project via the school district's internal media capabilities to educate students about prevention, detection, and screening for melanoma and other skin cancers by providing interactive information about melanoma and other skin cancers. Websites must be approved and listed by the school.
- (ME-2.1.6) Develop a partnership with a pharmaceutical company to launch a school-based skin cancer awareness campaign in conjunction with the company sunscreen product.

### **GOAL ME-3:**

**To increase the proportion of school districts that provide structural sun protection and have sun-safe environmental policies.**

#### **Objective ME-3.1:**

To survey and evaluate the facilities and policies of all school districts to determine which schools have structural sun protection and sun-safe environmental policies.

#### **Strategies:**

- (ME-3.1.1) Establish a baseline of school districts that have sun-safe policies and encourage improvement of their sun-safe policies where necessary.
- (ME-3.1.2) Build relationships with organizations with programs that can assist the school districts regarding the sun-safe environment, such as local shade tree commissions to provide trees for schools.

### **GOAL ME-4:**

**To promote worksite education by employers to employees on prevention, detection, and screening for melanoma and other skin cancers.**

#### **Objective ME-4.1:**

To partner with employers in providing employee education on prevention, detection, and screening for melanoma and other skin cancers.

**Strategies:**

- (ME-4.1.1) Create and track an awareness campaign encouraging employers statewide to provide employee education on prevention, detection, and screening for melanoma and other skin cancers.
- (ME-4.1.2) Pilot and implement presentations to employers, emphasizing those industries with “sun-exposed” employees, e.g., agricultural, construction, childcare, recreation, etc. and then roll out to other industries.

**GOAL ME-5:**

**To identify champions in the hospitality, recreation, and entertainment industries that provide public education to develop presentations on prevention, detection, and screening for melanoma and other skin cancers.**

**Objective ME-5.1:**

To survey the hospitality, recreation, and entertainment industries regarding their policies of providing public skin cancer education.

**Strategies:**

- (ME-5.1.1) Develop and implement a survey of the hospitality, recreation, and entertainment industries to learn how they educate their customers about proper sun care while visiting or enjoying entertainment at that establishment.
- (ME-5.1.2) Partner with identified industries to develop public education programs on prevention, detection, and screening for melanoma and other skin cancers.

**GOAL ME-6:**

**To educate the community on prevention, detection and screening for melanoma and other skin cancers.**

**Objective ME-6.1:**

To provide public health educational opportunities relating to skin cancer to the citizens of New Jersey at the local level.

**Strategies:**

- (ME-6.1.1) Develop, implement, and track community public health education programs on prevention, detection, and screening for melanoma and other skin cancers.
- (ME-6.1.2) Use public service announcements and media campaigns to educate the public on prevention, detection, and screening for melanoma and other skin cancers.

**TREATMENT**

**S**urgery remains the most effective treatment for melanoma. Radiation and chemotherapy have proven ineffective. Interferon is the only FDA-approved treatment for melanoma; however, it is generally used as an adjuvant therapy to surgery.

Any lesion considered suspicious should be removed for pathologic examination. Excision with removal of the entire lesion with a narrow margin of normal skin is the preferred method of biopsy (17). Incisional or punch biopsy is acceptable when it is not feasible to remove the entire lesion because of anatomic or cosmetic concerns. In these circumstances, the blackest area of a flat lesion and the thickest portion of a raised nevus should be sampled. Shave biopsies are not recommended when melanoma is suspected.

Clinical trials that have shown the most promise have centered on immunotherapy and bio-therapy (18-28). Both have shown measurable success. Autologous, polyvalent, and peptide vaccines have shown promise at

different disease stages and are being tested in clinical trials throughout the world (29-33).

Research has minimized the size of the excision required at the primary site. The introduction of the Sentinel Node Biopsy (SNB) has reduced the need for node resections, and the SNB has proven to be a very accurate predictor of metastatic disease (17). Recent testing of the TA90 glycoprotein antigen has also shown diagnostic promise. Dendritic Cell vaccinations in different combinations have been positive in early testing. Photographic Mole Mapping has become popular with high-risk patients as a monitoring device.

The critical issue, nevertheless, is that the overall cure rate for melanoma is low, and current research is resulting in treatment evolution at a rapid pace. As many clinical trials as possible should be made available in New Jersey to facilitate state-of-the-art treatment for all New Jerseyans. Information on the evolution of available treatment must be continually updated for medical professionals and patients alike.

**GOAL ME-7:**

**To ensure that all persons diagnosed with melanoma receive care from New Jersey hospitals and healthcare professionals with demonstrated proficiency in the diagnosis and treatment of melanoma.**

**Objective ME-7.1:**

To identify New Jersey Centers of Excellence in the diagnosis and treatment of melanoma.

**Strategies:**

- (ME-7.1.1) Determine what criteria will distinguish a Center or Provider as meeting Standards of Excellence for melanoma, whether it is existing criteria established by organizations such as the American College of Surgeons Commission on Cancer or developing new criteria.
- (ME-7.1.2) Promulgate a list of centers and healthcare providers who meet the Standards for Excellence for melanoma for public use, through such measures as a website, addendum to the existing Cancer Resource Guide, and a toll-free telephone number, etc.
- (ME-7.1.3) Provide recognition for those centers and providers meeting the Standards of Excellence for melanoma.
- (ME-7.1.4) Encourage those meeting the Standards of Excellence for melanoma to advertise their accomplishments.

**Objective ME-7.2:**

To develop resource material discussing melanoma treatment options and clinical trial information for patients.

**Strategies:**

- (ME-7.2.1) Promulgate state-of-the-art treatment options as essential considerations in the treatment of melanoma, such as sentinel node biopsy, interferon alpha-2b, and vaccine therapy.
- (ME-7.2.2) Encourage participation in clinical trials for melanoma.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

Melanoma and Skin Cancer Coalition: ME-1.1.1; ME-1.1.2; ME-1.1.3; ME-1.1.4; ME-1.2.1; ME-1.2.2; ME-1.2.3; ME-2.1.1; ME-2.1.2; ME-2.1.3; ME-2.1.4; ME-2.1.5; ME-2.1.6; ME-3.1.1; ME-3.1.2; ME-4.1.1; ME-4.1.2; ME-5.1.1; ME-5.1.2; ME-6.1.1; ME-6.1.2; ME-7.1.1; ME-7.1.2; ME-7.1.3; ME-7.1.4; ME-7.2.1

New Jersey Department of Health and Senior Services: ME-3.1.1; ME-4.1.1; ME-6.1.1; ME-6.1.2; ME-7.1.1; ME-7.1.2; ME-7.1.3; ME-7.1.4

Schering-Plough: ME-1.1.2; ME-1.1.3; ME-1.2.2; ME-2.1.2; ME-2.1.6; ME-5.1.2

## MELANOMA

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Awareness of diagnosis	1.1: Promote state-of-the-art diagnosis and treatment	ME-1.1.1						
		ME 1.1.2						
		ME-1.1.3						
		ME-1.1.4						
	1.2: Develop an alliance with businesses and organizations to develop media campaigns	ME-1.2.1						
		ME-1.2.2						
		ME-1.2.3						
2: Increase prevention behaviors among youth	2.1: Enhance School Curriculum	ME-2.1.1						
		ME-2.1.2						
		ME-2.1.3						
		ME-2.1.4						
		ME-2.1.5						
		ME-2.1.6						
3: Provide structural sun protection and sun-safe environmental policies	3.1: Survey/evaluate policies	ME-3.1.1						
		ME-3.1.2						
4: Promote worksite education	4.1: Partner with employees	ME-4.1.1						
		ME-4.1.2						
5: Identify Champions	5.1: Survey public education in the hospitality, recreation and entertainment industries	ME-5.1.1						
		ME-5.1.2						
6: Educate community	6.1: Provide public health education	ME-6.1.1						
		ME-6.1.2						
7: Treatment	7.1: Identify Centers of Excellence	ME-7.1.1						
		ME-7.1.2						
		ME-7.1.3						
		ME-7.1.4						
	7.2: Develop resource materials	ME-7.2.1						
		ME-7.2.2						

**Target Completion Date**

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## CHAPTER 11. Oral and Oropharyngeal Cancer

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## **ORAL AND OROPHARYNGEAL CANCER**

### **IMPORTANCE OF ORAL AND OROPHARYNGEAL CANCER FOR CANCER PREVENTION AND CONTROL**

**A**t the first meeting of the New Jersey Task Force on Cancer Prevention, Early Detection and Treatment, members voted to create a separate workgroup on oral and oropharyngeal cancer, although not mandated to do so in the Executive Order. Task Force members reasoned that oral and oropharyngeal cancer requires special attention. The public is less aware of cancers in this body region than of cancer in other sites. Initial detection of early lesions primarily involves dentists and dental auxiliaries rather than medical personnel. Furthermore, the anatomical location and adjacent structures present unique limitations on treatment options.

Oral and oropharyngeal cancer include cancer of the lip, tongue, floor of the mouth, palate, gingiva and alveolar mucosa, buccal mucosa, and oropharynx. It is estimated that oral and oropharyngeal cancer will account for up to 31,000 new cancer cases and 8,000 to 9,000 deaths (1-3), representing 2% to 3% of all cancer deaths (1;4;5). Males are approximately twice as likely as females to be diagnosed with and to die from oral and oropharyngeal cancer (3;4;6). Approximately 95% of oral and oropharyngeal cancer cases occur among persons over 45 years of age, and the average age of diagnosis is 60 years (5). Oral and oropharyngeal cancers are the sixth most common cancer among white males and the fourth most common among black males (1;7). From 1974 through 1997, trends in five-year relative cancer survival rates fluctuated around 56% for whites, 35% for blacks, and 54% for all races (3).

More than 90% of oral cancers are squamous cell carcinoma. About 5% are salivary gland malignancies, and smaller percentages are melanomas, sarcomas, and lymphomas. The primary focus of a cancer control program for oral and oropharyngeal cancers must, therefore, be on squamous cell carcinoma, the predominant type. National efforts to reduce morbidity and mortality associated with oral and oropharyngeal cancer center on two areas: primary prevention and early detection.

The known risk factors for oral and oropharyngeal squamous cell carcinoma are long-term tobacco use (1;5;7-16) alcohol use (1;5;7-14), immunosuppression (17), use of the betel (areca) quid popular in the Asian population (5;15;16;18) and in the case of lip cancer, long-term sun exposure (1;8-10). Evidence for consumption of fruits and vegetables as a protective factor is contradictory (1;10) and will thus not be addressed in this report. Immunosuppressed patients, particularly those diagnosed with HIV/AIDS, are at increased risk for many types of cancer that may present in the oral cavity and pharynx, including squamous cell carcinoma, Kaposi's sarcoma, and non-Hodgkin's lymphoma. Approximately 25% of patients diagnosed with oral and oropharyngeal cancers have none of these risk factors (14). Recent studies indicate that infection with human papillomavirus, particularly genotypes 16 and 18, may represent another independent risk factor (1;7;19;20).

The most significant indicator in predicting survival is stage of disease at time of diagnosis. Cases diagnosed in the early stages have a five-year survival rate of more than 75%, while cases diagnosed in the late

stages have a poor five-year survival rate of less than 25%(7)(11;12). According to National Cancer Institute (NCI) 1995 surveillance data, only one-third of cases are diagnosed in the early stages (5), whereas two-thirds have already spread regionally or have metastasized. For blacks, the statistics are far worse than for the population as a whole – over 80% of oral and oropharyngeal cancers in this segment of the population have regional or distant spread at the time of diagnosis (5).

In a recent study, approximately 81% of dentists said they provided an oral cancer examination for 100% of their patients 40 years of age or older at their initial appointment, and only 78% indicated they provided this examination at recall appointments (1). This study confirmed similar findings in a previous survey (10). It is clear that too few people have regular oral and oropharyngeal cancer examinations and that too few dentists and physicians are performing routine oral and oropharyngeal cancer exams.

A national strategic planning conference was recently held to begin addressing oral and oropharyngeal cancer (5). The national group convened for this conference determined that each state should develop a state model to address oral cancer education, prevention, and early detection. Maryland was the first state to pilot a state model (10). The goals, objectives, and strategies in this Plan are based on those developed by the national oral cancer group (21).

## **ORAL AND OROPHARYNGEAL CANCER IN NEW JERSEY**

**Incidence.** New Jersey mirrors the national average for oral and oropharyngeal cancer incidence. Since the mid-1980s, New Jersey and US incidence rates for oropharyngeal cancer have been declining. For New Jersey males, incidence rates are higher among blacks than whites. In 2000\*, the incidence rate for black males was 23.5 per 100,000\*\* compared to 14.0 per 100,000\*\* for white males. Males have traditionally had higher incidence rates than females in New Jersey, although in recent years the gap is narrowing due to the increasing number of women who began smoking over the past three decades (Figure 1). Incidence rates for females in New Jersey have generally been similar among races. In 2000\*, black females had an incidence rate of 5.1 per 100,000\*\* compared to 5.5 per 100,000\*\* for white females (Figure 1).

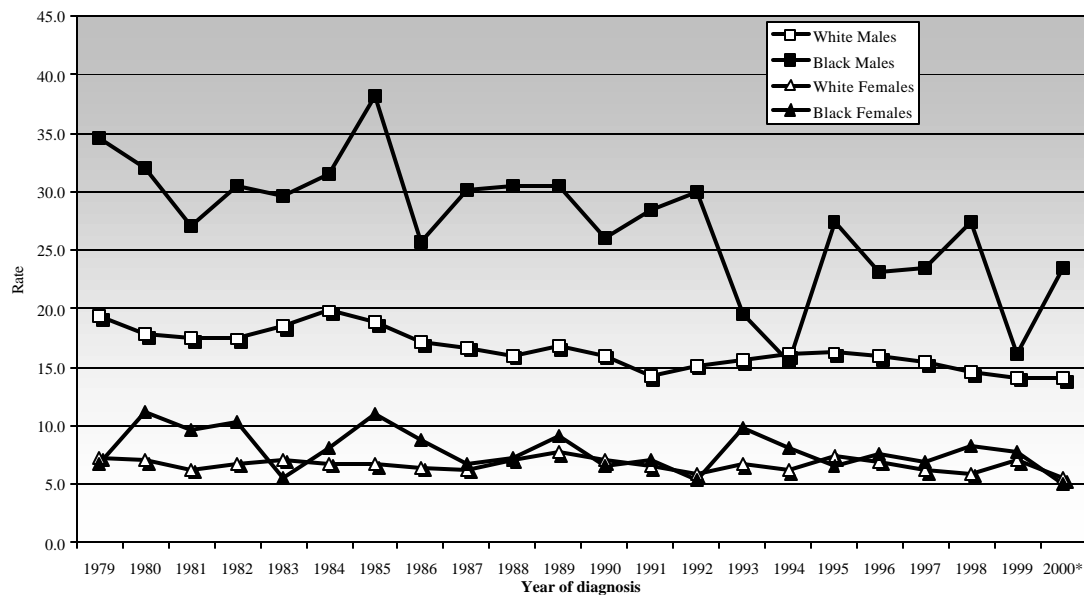
For all stages combined, the five-year relative survival rate for oral and oropharyngeal cancer is 53% (22). With early detection, survival rates are considerably higher. The five-year survival rate for oral and oropharyngeal cancer diagnosed with localized disease is 81% (22). In 2000\*, approximately 54% of those with oral and oropharyngeal cancer were diagnosed in the late stages according to the New Jersey State Cancer Registry. Dentists and primary care physicians can recognize abnormal tissue changes and detect cancer at earlier stages during regular checkups.

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\*Incidence rates for year 2000 data from the New Jersey State Cancer Registry are preliminary.

\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. standard.

**Figure 1: New Jersey Incidence Rates for Oropharyngeal Cancer by Gender and Race, 1979-2000\***



Source: New Jersey State Cancer Registry (NJSCR); Rates are per 100,000 and age-adjusted to the 2000 US (5-year groups) standard.

\* Incidence rates for the year 2000 data from the NJSCR are preliminary.

In a study of New Jersey patients with AIDS, approximately 6% also had a cancer. Of these, 50% had Kaposi's sarcoma, 33% had non-Hodgkin's lymphoma, and 17% had lung, oral, and other cancers. This subgroup requires special consideration with regard to diagnosis and management and is discussed separately in the chapter on Emerging Issues (17).

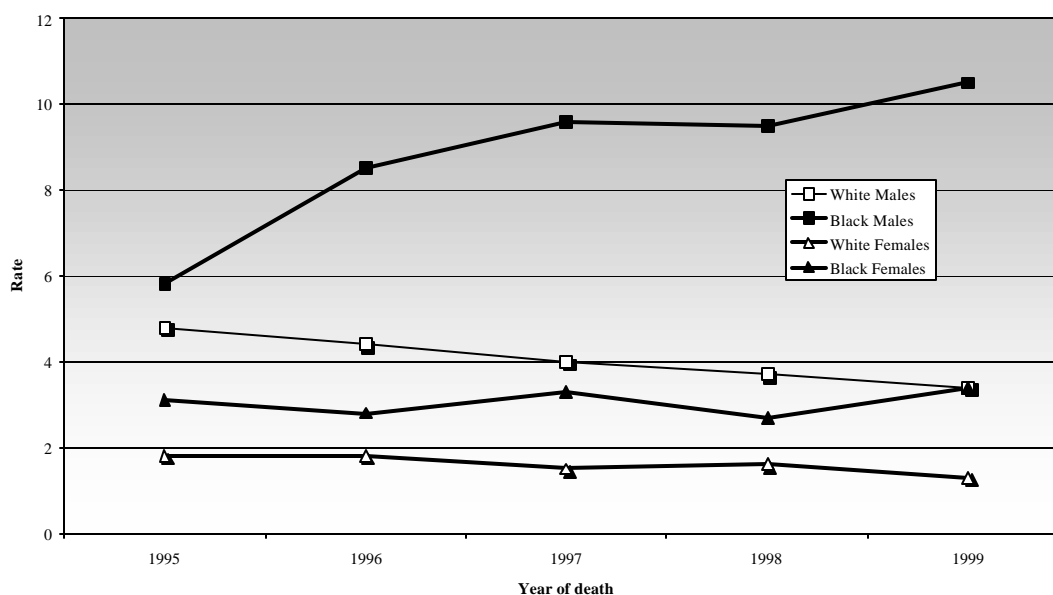
**Mortality.** Overall, oral and oropharyngeal cancer deaths in New Jersey mirror the decrease seen in the U.S. In 1999, New

Jersey males (all races combined) had a mortality rate of 4.0 per 100,000\*\* and New Jersey females had a mortality rate of 1.5 per 100,000\*\*. However, mortality rates differ dramatically by race. Mortality rates for New Jersey black males increased from 5.8 per 100,000\*\* in 1995 to 10.5 per 100,000\*\* in 1999; mortality rates for white males declined consistently from 4.8 per 100,000\*\* in 1995 to 3.4 per 100,000\*\* in 1999 (Figure 2). The mortality rates for females in New Jersey remained relatively stable between 1995 and 1999 (Figure 2).

\*Incidence rates for year 2000 data from the New Jersey State Cancer Registry are preliminary.

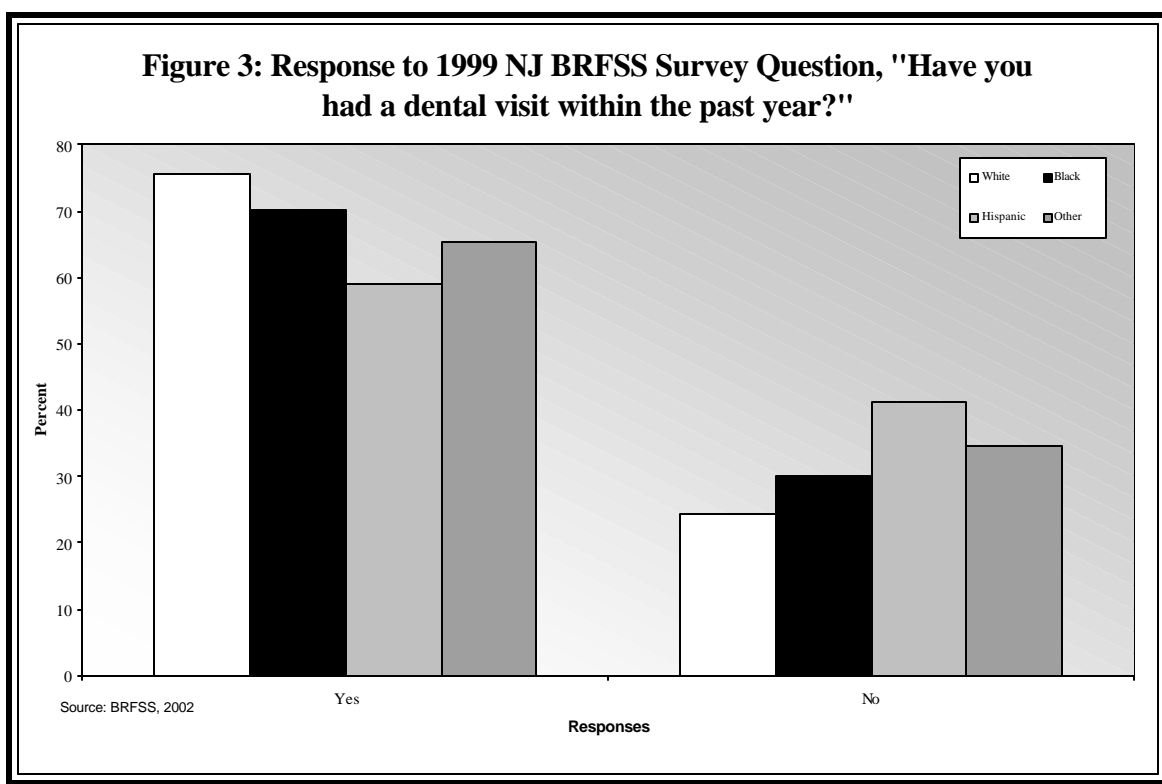
\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. standard.

**Figure 2: New Jersey Mortality Rates for Oropharyngeal Cancer by Race and Gender, 1995-1999**



According to the 1999 Behavioral Risk Factor Surveillance System (BRFSS), 72.3% of New Jersey residents visited a dentist or dental clinic in 1999. Since a majority of residents are already visiting dentists, an opportunity exists to increase the number of routine oral cancer examinations in this setting. No differences are observed for gender or age, and dental visits are positively

associated with education and income level. When these data are analyzed by race, a disparity in dental care in New Jersey becomes evident (Figure 3). Among respondents who answered 'no' to the question, "Have you had a dental visit within the past year?", 24.4 % were white, 29.9% were black, 41.1% were Hispanic and 34.7% were 'Other'.



To target oral and oropharyngeal cancer in the New Jersey region, the Oral Cancer Consortium was formed in 1998 by a group of professional and public health organizations and agencies united by a common mission. The Oral Cancer Consortium is dedicated to the prevention, early detection, and discovery of the biological basis and treatment of oral and oropharyngeal cancer among the citizens they serve and society at large. To educate healthcare professionals and the public about the importance of comprehensive oral and

oropharyngeal examinations, the Consortium will emphasize the following: community outreach to increase public awareness, prevention to change habits and environmental factors, early detection to effect the highest cure rates, clinical trials to develop best treatment practices, research into the biological basis for disease to prevent occurrence, and application of outcomes in treatment to cure the disease in affected populations.



Below is the Healthy New Jersey 2010 goal relating to oral and oropharyngeal cancer.

**Healthy New Jersey Goal: Reduce the percentage of oral and oropharyngeal cancer diagnosed in the late (regional and distant) stages of disease to 40.0 % for all males and 35.0% for all females by 2010.**

**Table 1. Baseline data and projected target rates to reduce the diagnosis of oral cancer in the late stages of disease.**

<b>Populations</b>	<b>1998 Baseline Data</b>	<b>Target</b>	<b>Percent Change</b>	<b>Preferred 2010 Endpoint</b>	<b>Percent Change</b>
White Males	51.2	40.0	-21.9	20.0	-60.9
Black Males	58.5	40.0	-31.6	20.0	-65.8
White Females	39.0	35.0	-10.3	15.0	-61.5
Black Females	41.9	35.0	-16.5	15.0	-64.2

*Source: Healthy New Jersey 2010*

In support of the Healthy New Jersey 2010 goal for oral and oropharyngeal cancer, the recommendations of the Oral and Oropharyngeal Cancer Workgroup are summarized below for the following four topic areas in priority order:

- Public Awareness
- Public Access
- Professional Awareness and Education
- Research and Surveillance

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## GOALS, OBJECTIVES AND STRATEGIES

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### PUBLIC AWARENESS

The Oral and Oropharyngeal Cancer Workgroup defined public awareness and education as the highest priority in oral and oropharyngeal cancer control in New Jersey. Early detection and treatment methods are highly successful in reducing the morbidity and mortality from oral and oropharyngeal cancer (23). It is therefore essential to raise public awareness about lifestyle behaviors that put them at increased risk. The public must also be informed about the signs and symptoms of oral and oropharyngeal cancer. Finally the public needs to know about professionals and facilities that employ proven, state-of-the-art early detection and treatment methods.

A large segment of the public is unaware of the early signs of oral and oropharyngeal cancer, and the population at highest risk is least aware (24)(25;26). Most adults are also poorly informed about risk factors and the need for ongoing screening to detect early lesions. The 1990 National Health Interview Survey, Health Promotion and Disease Prevention Supplement, found that this general lack of knowledge and misinformation was common among U.S. adults, regardless of age, race, or ethnicity (25). Of the adults surveyed, 40% did not know any of the signs of oral and oropharyngeal cancer; another 25% correctly identified only one. Only 13% of those surveyed identified regular alcohol drinking as a risk factor for oral and oropharyngeal cancer. Even though two-thirds of respondents cited tobacco use as a risk factor for oral and oropharyngeal cancer, a greater number of respondents correctly identified smoking as a risk factor for heart disease, emphysema, or lung cancer than for oral and oropharyngeal cancer. Similarly,

few respondents recognized heavy drinking as a risk factor for throat and mouth cancer, although 83% knew heavy drinking increases risk for cirrhosis of the liver (25).

Oral and oropharyngeal cancer questions included in a pilot study about general oral and oropharyngeal health among 700 adults once again uncovered the fact that respondents were not well informed about risk factors (27). When asked, 'Which of the following are early warning signs of mouth or lip cancer?', only 63% correctly identified 'a white or red patch in the mouth that does not go away', and 20% responded 'don't know/not sure' on the question. Only 49% indicated that regular use of both tobacco and alcohol were risk factors; 29% incorrectly responded that having a relative who has had mouth or lip cancer was a risk factor. These studies clearly demonstrate the need for improved public education and awareness efforts for oral and oropharyngeal cancer.

Although the overall level of knowledge about risk factors for oral and oropharyngeal cancer is low, adults who had a higher level of knowledge of risk factors for oral and oropharyngeal cancer were more likely to have had an oral and oropharyngeal cancer examination (28). These findings are consistent with trends seen for other cancers, including cervical, breast, and colorectal, suggesting that conducting comprehensive educational interventions might increase the number of oral and oropharyngeal cancer examinations being conducted (29). The 1992 National Center for Health Statistics Cancer Supplement Survey found that only 14% of the public responded that they had been examined for oral cancer (30), indicating the need for increased awareness of risk factors of oral cancer and the importance of

screening. This survey also revealed that the groups least likely to have been examined were blacks or Hispanics, those with low levels of education, persons 65 years of age or older, current users of tobacco products (30), and respondents with a low level of knowledge about risk factors for oral and oropharyngeal cancer (28).

Currently in New Jersey, additional public awareness and education efforts for oral and oropharyngeal cancer are needed to enhance those already under way. The Oral Cancer Consortium, whose mission includes raising awareness in the general public, conducts an annual screening that is widely advertised. The New Jersey Dental Association's statewide programs for Children's Dental Health Week expose New Jersey children to important information about tobacco and proper diet, as well as care of teeth and gingiva. The mission of New Jersey Breathes Tobacco Control Coalition, a statewide 47-member agency, is to alter the social norm of tobacco acceptance fostered by the tobacco industry. Through awareness and education, New Jersey Breathes is providing support for tobacco control policies, increased tobacco taxes, and increased access to nicotine treatment, with the ultimate goal of reducing tobacco consumption, thus improving the health of New Jersey residents. Any new tobacco control and oral health programs should build on existing activities, such as those of the New Jersey Comprehensive Tobacco Control Program (31-33). Existing activities are insufficient, as oral and oropharyngeal cancer incidence and mortality have remained steady over the past several years (Tables 1 and 2).

The Oral and Oropharyngeal Cancer Workgroup recognizes the importance of enhancing public awareness efforts already under way in New Jersey. Although cognizant of the fact that this is only the

beginning of a continuous, dynamic process, the workgroup proposes two areas in which funds and resources can be dedicated to begin work. First, the workgroup suggests concentrating education and awareness efforts on the population at highest risk. Research has shown that this type of health promotion is necessary to enhance oral and oropharyngeal cancer prevention and early detection (24). Targeting high-risk segments of the population for educational programs can be done by first determining areas of the state where pockets of at-risk individuals reside and then reviewing and improving existing educational materials for use with this population. To enhance work being done during Children's Dental Health Week, scholastic education about oral and oropharyngeal cancer should be a component of the standard curriculum. Most importantly, it is essential to collaborate with national and local organizations that have made oral and oropharyngeal cancer education and awareness part of their mission, such as the Oral Cancer Consortium, American Dental Association, and New Jersey Breathes. Through collaboration, media campaigns can be implemented and high-risk populations can be well targeted.

Secondly, the Oral and Oropharyngeal Cancer Workgroup proposes to work on strengthening laws and regulations concerning tobacco and alcohol, the two primary risk factors for oral and oropharyngeal cancer. Tobacco and alcohol exposure can be limited by promoting no-smoking laws and by making the public more aware of the direct association between use of these substances and oral cancer. Additionally, more stringent regulation would decrease accessibility of these substances.

Without accurate and appropriate information about oral and oropharyngeal cancer, New Jerseyans, regardless of age, race, or ethnicity, cannot make informed decisions

about their own health, including the need to seek out an oral and oropharyngeal cancer examination (26;34). By improving the knowledge of the general public about the risk factors, signs, and symptoms of oral and oropharyngeal cancer, all populations will be positively influenced (24). It is nevertheless critical that education efforts be designed to

reach those identified as least likely to receive oral and oropharyngeal cancer examinations. Thus, the Oral and Oropharyngeal Cancer Workgroup proposes to begin this endeavor with the following goal, objectives, and strategies.

### **GOAL OR-1:**

**To heighten public awareness and knowledge of oral and oropharyngeal cancer and the need for early detection in New Jersey.**

### **Objective OR-1.1:**

To increase direct public education to groups at high risk for oral and oropharyngeal cancer.

### **Strategies:**

- (OR-1.1.1) Collaborate with the Oral Cancer Consortium and other agencies to coordinate and support national oral and oropharyngeal cancer awareness and education campaigns.
- (OR-1.1.2) Review the limited number of oral and oropharyngeal cancer educational materials currently available for specific target groups and assess their accuracy, comprehensiveness, reading level, and acceptability.
- (OR-1.1.3) Encourage addition of comprehensive oral and oropharyngeal cancer education as an essential component to elementary and secondary school health curricula across New Jersey.
- (OR-1.1.4) Work with the American Dental Association, the Oral Cancer Consortium, and the New Jersey Dental Association in their endeavors to create a media campaign to increase awareness of oral and oropharyngeal cancer in the general public.
- (OR-1.1.5) Work with the addictions treatment programs surrounding tobacco, alcohol, and other drugs to increase awareness of oral and oropharyngeal cancer in these high-risk populations.
- (OR-1.1.6) Place a member of the Oral and Oropharyngeal Cancer Implementation Workgroup on New Jersey Breathes in order to collaborate with leading tobacco control advocates and to support Oral Health Funding from a larger collaborative.

**Objective OR-1.2:**

To strengthen tobacco and alcohol laws and regulations.

**Strategies:**

- (OR-1.2.1) Work with New Jersey Breathes to promote tobacco control standards that include oral and oropharyngeal cancer.
- (OR-1.2.2) Encourage warning labels on tobacco and alcohol products to include oral and oropharyngeal cancer risk factors.
- (OR-1.2.3) Reinforce no-smoking laws and encourage more comprehensive regulation of tobacco products.
- (OR-1.2.4) Expand legislation promoting indoor and outdoor smoke-free environments.
- (OR-1.2.5) Support the reduction of youth access to tobacco through Tobacco Age of Sale Enforcement (TASE) Operations and alcohol through the “We Check 21” Program.
- (OR-1.2.6) Support the increase of tobacco and alcohol taxes.
- (OR-1.2.7) Work with the National Council on Alcohol and Drug Dependency (NCADD) of New Jersey to incorporate oral and oropharyngeal cancer issues in alcohol control advocacy standards.

**PUBLIC ACCESS**

The chapter on Access and Resources clearly demonstrates the need for better access and resources for cancer screening, early detection, and treatment in New Jersey. Since oral and oropharyngeal cancer is one of the most preventable and treatable cancers, improving access and resources is essential to decreasing morbidity and mortality from oral and oropharyngeal cancer. Even if public awareness can be heightened (Goal OR-1) and even if dentists and physicians can be better educated and motivated (Goal OR-3), access issues are likely to persist as obstacles to early detection of oral and oropharyngeal cancer (35).

The incidence and mortality data presented earlier in this chapter demonstrate that disparities exist in race and gender. Given the stark differences between oral and oropharyngeal cancer stage at diagnosis and survival data between the nation’s black and white populations, as well as the relationship between socioeconomic level and oral and oropharyngeal cancer survival, access must be considered as a possible factor.

For oral and oropharyngeal cancer in particular, two underlying problems directly affect access and resources for cancer control in New Jersey. First, a comprehensive oral and oropharyngeal cancer needs and capacity assessment does not exist. Without a needs

and capacity assessment, it is difficult to determine why New Jersey residents are not receiving the oral and oropharyngeal cancer care they need and which populations are most affected. Barriers, such as socioeconomic and attitudinal, exist and many segments of the population do not benefit from existing programs in the state. Second, not enough dentists serve the high-risk population. The lack of availability of dentists in specific urban and rural areas in New Jersey is demonstrated by several areas of the state being designated as Dental Health Professional Shortage Areas (36;37).

The Oral Cancer Consortium, described earlier in this chapter, has recognized these problems as well. Currently, the 22 member organizations of the Oral Cancer Consortium are conducting and promoting free oral and oropharyngeal cancer screening events to improve access to care. The Consortium strives to increase the number of patients being screened, increase the number of facilities offering free screening, and improve access to screening for populations at high risk. Additionally, the Consortium is offering public and professional educational programs in early detection of oral and oropharyngeal cancer. However, without a secure source of ongoing funding, the Consortium will not be able to reach the entire dental community, and efforts to educate the general public will be limited.

To complement the work being done by the Oral Cancer Consortium, the Oral and Oropharyngeal Cancer Workgroup proposes the following. First, the Oral and Oropharyngeal Cancer Workgroup and the Oral Cancer Consortium must partner to begin centralizing the oral and oropharyngeal cancer efforts within New Jersey.

Second, we propose that hospitals be used as access points to provide at-risk patients with oral and oropharyngeal cancer screening. The Oral and Oropharyngeal Cancer Workgroup recognizes that population segments at highest risk for oral and oropharyngeal cancer may overlap significantly with groups of individuals unlikely to voluntarily seek screening and unlikely to routinely visit a primary care physician and/or dentist. Individuals who may not seek routine medical and dental examinations may become patients at hospitals as a result of illness or accidents. Admission to the hospital may provide the opportunity to screen these patients, particularly those at increased risk for oral and oropharyngeal squamous cell carcinoma. To target populations that might otherwise utilize oral and oropharyngeal cancer screening, but are not doing so because of barriers, the Oral and Oropharyngeal Cancer Workgroup proposes that examinations and screenings be offered in conjunction with other existing services, such as screening for other types of cancer and at meetings for addicted populations.

Third, the Oral and Oropharyngeal Cancer Workgroup recommends that general dental residency programs in New Jersey, particularly those serving urban populations, be supported. Currently, residency programs are supported by aid from the federal government from Medicare reimbursement. Direct medical education aid (DME) and indirect medical education aid (IME) support residency positions. Hospitals support the programs to a certain extent as well. Saint Joseph's Regional Medical Center found that DME and IME offset much of the hospital's expense, and residents can easily justify their existence financially, even in hospitals where most patients are on New Jersey Charity Care or Medicaid.

However, additional dental residency slots in urban hospitals are needed to develop screening programs for all hospital-admitted patients. This approach to widespread oral cancer screening also requires a multidisciplinary protocol involving the Emergency Department and the medical and surgical services at these hospitals. Therefore, funding is needed to increase the number of residents to provide essential professional human resources in order to deliver diagnostic care and treatment to this underserved segment. This early experience will also better prepare young dentists to assume leadership roles in cancer prevention, detection, and care throughout their professional careers.

New Jersey must improve access to oral and oropharyngeal cancer screening and must outreach to all segments of the population. Existing data are inadequate to quantify the relative contributions made by risk factors and barriers to care (e.g., access to prompt and accurate diagnosis and appropriate care, nutrition and general health, genetics, use of alcohol and tobacco, etc.). The differences noted between black and white New Jersey residents in oral and oropharyngeal cancer incidence and mortality must be further investigated in order to improve access to care for all populations. The following goal, objective, and strategies are offered to begin the process of improving access and resources for oral and oropharyngeal cancer care.

#### **GOAL OR-2:**

**To increase access to oral and oropharyngeal cancer screening and the ability to reach all segments of the population.**

#### **Objective OR-2.1:**

To increase community outreach for oral and oropharyngeal cancer screening.

#### **Strategies:**

- (OR-2.1.1) Partner with the Oral Cancer Consortium to determine areas in which collaboration on screening can be effective.
- (OR-2.1.2) Use the hospital as an access point and develop protocols in these institutions for the oral and oropharyngeal examination of every at-risk patient admitted, beginning with those hospitals with dental residency programs. Additionally, appropriate protocols should be adapted and spread to hospitals that do not have dental residency programs.
- (OR-2.1.3) Piggy-back oral and oropharyngeal cancer examinations onto existing outreach programs to increase screening without creating substantial cost fluctuation, by using the following venues: mobile units, outpatient facilities run by medical center, nursing homes and assisted-living facilities, free oral and oropharyngeal cancer screenings in major urban hubs, free oral and oropharyngeal cancer screenings in remote and underserved areas, and free oral and oropharyngeal cancer screenings at meetings for those with addictions.

- (OR-2.1.4) Partner with New Jersey Department of Health and Senior Services Division of Addiction Services and addictions providers to disseminate oral and oropharyngeal cancer education to “12 Step” groups.

## **PROFESSIONAL AWARENESS AND EDUCATION**

**M**ortality from oral and oropharyngeal cancer has remained high and, in contrast to nearly every other form of cancer, survival has not improved over the last 40 years, despite significant advances in cancer treatment. It is generally acknowledged that only primary prevention and early detection offer significant opportunities for improving survival statistics and the quality of life of survivors (12). (The role of healthcare providers in primary prevention is dealt with earlier in this report.) Of the many obstacles to early detection of oral and oropharyngeal cancer, one that can be overcome is the current inadequacy of education and training among healthcare providers. There is strong evidence that professional awareness, education, training, and motivation fall below desirable levels (11). Studies have shown that dentists are not as knowledgeable about oral cancer prevention and early detection as they could be and that they recognize these deficiencies (8). As noted earlier, many dentists do not provide annual oral cancer examinations, even though they recognize their importance (1;10). Furthermore, preliminary oral cancer training in medical schools lacks both adequacy and comprehensiveness (9).

While organized dentistry is beginning to acknowledge this responsibility, there appears to be no strong incentive for any group of clinicians to make oral and oropharyngeal cancer detection a priority in the way that dermatologists have for skin cancer detection. As dentistry is beginning to take ownership of

this issue, the upgrading of awareness, education, training, and motivation should be applied across many disciplines, including family practice and internal medicine.

The Oral and Oropharyngeal Cancer Workgroup offers three goals by which the involvement of dentists, hygienists, physicians, and nurses in the prevention and early detection of oral and oropharyngeal cancer can be upgraded to have a significant impact on mortality and quality of life for survivors. First, we propose that professional awareness and education about oral and oropharyngeal cancer begin with young professionals in medical and dental schools in New Jersey. Second, practicing clinicians should be educated and re-educated about comprehensive oral and oropharyngeal cancer examinations through continuing medical education classes. Third, to ensure that practicing clinicians are receiving training for oral and oropharyngeal cancer, the Workgroup recommends that this type of professional education be added to the licensure requirements.

As stated in the public awareness section of this chapter, it is essential that high-risk populations be targeted. One method to reach specific populations is to educate professionals about the high-risk populations and make them more aware of the need to outreach to special populations. Education should particularly focus on lower socioeconomic status populations and populations residing in areas with limited access to oral health services. Additionally, blacks with oral and oropharyngeal cancer have significantly more advanced disease at the



time of detection and a higher mortality rate after detection; therefore education and awareness efforts should target this population. Over the last 40 years, the proportion of oral and oropharyngeal cancer patients who are women has more than doubled, now comprising approximately one-third. The education of clinicians who focus

on women's issues should, therefore, not be overlooked.

The Oral and Oropharyngeal Cancer Workgroup offers the following goal, objectives, and strategies to address needs in professional awareness and education relating to oral and oropharyngeal cancer.

### **GOAL OR-3:**

**To upgrade involvement of all dentists and hygienists and those physicians in appropriate specialties in the prevention and early detection of oral and oropharyngeal cancer by increasing the current level of awareness, education, training, and motivation among oral and oropharyngeal healthcare providers.**

#### **Objective OR-3.1:**

To provide appropriate education on oral and oropharyngeal cancer to physicians, dentists, and hygienists in training.

#### **Strategies:**

- (OR-3.1.1) Develop a core curriculum for physicians, dentists, and hygienists on the primary prevention and early detection of oral and oropharyngeal cancer including alcohol and tobacco studies.
- (OR-3.1.2) Promote the adoption of this oral health program in New Jersey's medical and dental schools and in medical primary care residency programs and dental residency programs throughout the state.
- (OR-3.1.3) Support advanced training programs in Oral Medicine.

#### **Objective OR-3.2:**

To update and upgrade the knowledge and awareness of New Jersey's practicing clinicians in the area of oral and oropharyngeal cancer.

**Strategies:**

- (OR-3.2.1) Develop a continuing education program for dentists, hygienists, and interested physicians on the primary prevention and early detection of oral and oropharyngeal cancer.
- (OR-3.2.2) Introduce the continuing education (CE) program on oral and oropharyngeal cancer through existing, already funded CE providers (see below).

**Objective OR-3.3:**

To assure the citizens of New Jersey that all licensed dentists in the state have adequate baseline knowledge of oral and oropharyngeal cancer prevention and early detection.

**Strategies:**

- (OR-3.3.1) Recommend to the New Jersey Board of Dentistry that oral and oropharyngeal cancer education be part of the 40-hour requirement for license renewal every two years.
- (OR-3.3.2) Partner with organizations, such as the Oral Cancer Consortium, the New Jersey Dental Association, University of Medicine and Dentistry of New Jersey, Seton Hall University, among others, to gain support for licensure requirements for oral and oropharyngeal cancer education.

**RESEARCH AND SURVEILLANCE**

Research needed on oral and oropharyngeal cancer centers on both public health issues and basic biomedical research. Included in public health issues are studies to better understand the epidemiology of this disease and outcomes assessments of early detection and intervention on survival. On the biomedical side, a better understanding of basic biological processes underscoring the natural history of this disease and development of novel treatment strategies are prime targets.

New Jersey, while experiencing lower incidence of the disease than the nation as a whole, nevertheless has a higher mortality, with cases being diagnosed at later stages, as

demonstrated earlier in this chapter. Epidemiological research will identify the populations at higher risk and will help target susceptible populations for early detection and intervention. Research into the outcomes assessment of risk reduction interventions and early detection in oral and oropharyngeal cancer will guide policy for broader application.

The histologic type of oral and oropharyngeal cancer is predominantly squamous cell carcinoma, comprising greater than 90% of cases. Prior to development of frank carcinoma, a progression of lesions from hyperplastic to dysplastic to carcinoma-in-situ is believed to be the common pathway leading to squamous cell carcinoma. Little is understood of the genetic events leading to

the development of squamous cell carcinoma. Efforts should be directed toward understanding basic biologic processes that lead to development and progression of this entity. Identification of reliable biomarkers that influence prognosis and response to treatment, as seen with many other cancers, is lacking in oral and oropharyngeal cancer. Within the state are significant resources for biologic research in both our public and private universities and other entities. No known effective chemotherapy exists for this disease. New Jersey is a powerhouse in the pharmaceutical industry, which represents a

potent resource for exploitation of discovery of new biologic information.

The Workgroup's recommendation is, therefore, to encourage and support research on the epidemiology of oral and oropharyngeal cancer, the impact of early detection and intervention on oral and oropharyngeal cancer, the pathogenesis of progression or regression of dysplastic lesions in oral and oropharyngeal cancer, chemo-prevention of oral and oropharyngeal cancer, and the development of improved technologies in identifying and characterizing oral and oropharyngeal cancer.

#### **GOAL OR-4:**

**To identify target groups for oral and oropharyngeal cancer that maximize interventional and educational impact while permitting cost-effectiveness evaluation.**

#### **Objective OR-4.1:**

To assess knowledge of oral and oropharyngeal cancer and screening in the public and professional sectors.

#### **Strategies:**

- (OR-4.1.1) Survey a random sample of the New Jersey population to measure knowledge of oral and oropharyngeal cancer risks, signs, and recollection of oral and oropharyngeal cancer examinations. The survey will include demographic and geographic variables to assess bias in the sampling procedure.
- (OR-4.1.2) Survey healthcare practitioners in New Jersey to measure knowledge of oral and oropharyngeal cancer risks, signs, and screening guidelines for oral and oropharyngeal cancer examinations.
- (OR-4.1.3) Evaluate practitioners' competency in performing oral and oropharyngeal cancer examinations regarding detection of premalignancies and oral and oropharyngeal cancer and treatment using the protocol for training in the Consortium for the Prevention and Detection of Oral Cancer.

**Objective OR-4.2:**

To document prevalence of risk factors for oral and oropharyngeal cancer in New Jersey.

**Strategies:**

- (OR-4.2.1) Use BRFSS and other data sources (such as the National Health and Nutrition Examination Survey) to analyze the prevalence of tobacco and alcohol use, as well as nutritional habits, in New Jersey populations.
- (OR-4.2.2) Conduct a scientific research study to measure the correlation between outcomes and factors required for optimal management of patients with oral and oropharyngeal cancer.
- (OR-4.2.3) Work with the Oral and Oropharyngeal Cancer Implementation Workgroup to distribute recommendations for optimal treatment to healthcare professionals, New Jersey Department of Health and Senior Services, and involved public health organizations.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

New Jersey Dental Association: OR-3.3.1; OR-3.3.2

New Jersey Department of Health and Senior Services: OR-1.1.1; OR-1.1.2; OR-1.1.3; OR-1.1.4; OR-1.2.1; OR-1.2.2; OR-1.2.3; OR-1.2.4; OR-1.2.5; OR-1.2.6; OR-2.1.4; OR-4.1.1; OR-4.2.1; OR-4.3.1; OR-4.4.1; OR-4.4.2; OR-4.4.3

Oral Cancer Consortium: OR-1.1.1; OR-1.1.2; OR-1.1.3; OR-1.1.4; OR-2.1.1; OR-2.1.2; OR-2.1.3; OR-3.3.1; OR-3.3.2; OR-4.1.1; OR-4.2.1; OR-4.4.1

Seton Hall University: OR-1.1.5; OR-2.1.2; OR-2.1.3; OR-3.1.1; OR-3.1.2; OR-3.1.3; OR-3.2.1; OR-3.2.2; OR-3.3.1; OR-3.3.2

University of Medicine and Dentistry of New Jersey – Dental School: OR-1.1.1; OR-1.1.2; OR-1.1.3; OR-1.1.4; OR-1.1.5; OR-2.1.1; OR-2.1.2; OR-2.1.3; OR-3.1.1; OR-3.1.2; OR-3.1.3; OR-3.2.1; OR-3.2.2; OR-3.3.1; OR-4.1.1; OR-4.2.1; OR-4.3.1; OR-4.4.1; OR-4.4.2; OR-4.4.3

## ORAL AND OROPHARYNGEAL

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Heighten public awareness and knowledge	1.1: Increase direct public education to high-risk groups	OR-1.1.1						
		OR-1.1.2						
		OR-1.1.3						
		OR-1.1.4						
		OR-1.1.5						
		OR-1.1.6						
	1.2.: Strengthen tobacco/alcohol laws and regulations	OR-1.2.1						
		OR-1.2.2						
		OR-1.2.3						
		OR-1.2.4						
		OR-1.2.5						
		OR-1.2.6						
		OR-1.2.7						
2: Increase access to screening	2.1: Increase community outreach	OR-2.1.1						
		OR-2.1.2						
		OR-2.1.3						
		OR-2.1.4						
3: Increase involvement of healthcare providers through education	3.1: Provide education for training	OR-3.1.1						
		OR-3.1.2						
		OR-3.1.3						
	3.2: Update knowledge of practicing clinicians	OR-3.2.1						
		OR-3.2.2						
	3.3: Assure baseline knowledge by licensees	OR-3.3.1						
		OR-3.3.2						
4: Identify groups that maximize impact while cost effective	4.1: Assess knowledge in public/private sectors	OR-4.1.1						
		OR-4.1.2						
		OR-4.1.3						
	4.2: Document prevalence of risk factors	OR-4.2.1						
		OR-4.2.2						
		OR-4.2.3						

Target Completion Date

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## PROSTATE CANCER

### IMPORTANCE OF PROSTATE CANCER FOR CANCER PREVENTION AND CONTROL

Prostate cancer is the second lead cause of cancer deaths in U.S. men, and the number one type of new cancer cases in U.S. men (1). Evidence suggests, through autopsy studies, that a substantial number of men have prostate cancer that is undiagnosed (2;3). Cancer of the prostate is the most prevalent of all cancers in men because of slow tumor growth rate and improved survival rate.

Risk factors that predispose men to prostate cancer are older age, black race, and a family history of prostate cancer (a history of having an affected first-degree relative at least doubles the risk) (4). According to the American Cancer Society, about 70% of all men with clinically diagnosed prostate cancer are aged 65 years or older (5). Because prostate cancer usually occurs at an age when conditions such as heart disease and stroke cause death, many men die *with* prostate cancer rather than *from* it. Fewer than 10% of men with prostate cancer die of the disease within five years of diagnosis. Black men develop prostate cancer at a higher rate than men in any other racial or ethnic group but the reasons for the higher rate remain unknown. Black men are also far more likely than other men to die of this disease. In the years 1992-1998, 53.1 of every 100,000 black men died of prostate cancer compared with 22.4 of every 100,000 white men, 15.9 of every 100,000 Hispanic men, 14.0 of every 100,000 American Indian men, and 9.8 of every 100,000 Asian/Pacific Islander men (1).

Although the risk factors for prostate cancer are inherent and therefore not preventable, certain tests can be performed for early diagnosis and screening. In 1986, the Food

and Drug Administration approved the Prostate Specific Antigen (PSA) test as a method to monitor prostate cancer progression. The PSA test permitted the detection of latent and preclinical cancers that cannot be detected by clinical means. As a result, a large number of prostate cancers have been diagnosed that would never have been detected clinically (latent) or were detected earlier than clinical detection would have allowed (preclinical) (6). Scientific consensus has not been reached on the effectiveness of prostate cancer screening in reducing deaths, and effective measures to prevent prostate cancer have not yet been determined.

Guidelines for prostate cancer are controversial primarily because of lack of evidence from randomized trials that early detection and aggressive treatment of prostate cancer can reduce mortality (4). Other controversies exist because PSA testing frequently detects prostate cancer in older men, who may well die of other causes long before they are affected by the slow-growing prostate tumor that might otherwise have gone undetected. Additionally, as with other screening mechanisms, patients must contend with the possibility of false positives, anxiety over false positives, drawbacks to aggressive treatment, and the burden of dealing with a cancer that might never have been discovered or affected the patient during his natural life.

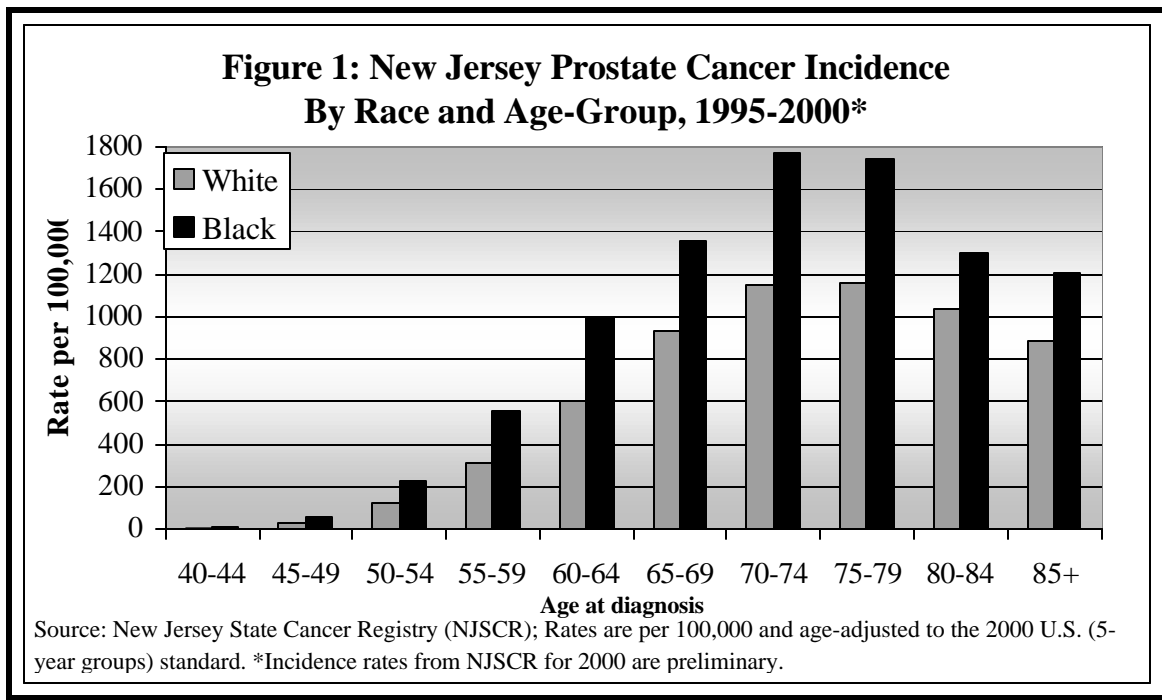
Many physicians recommend screening to their patients, and in recent years a substantial proportion of men in the United States have been screened for prostate cancer with PSA, Digital Rectal Exam (DRE), or both. Although screening detects some prostate cancers early in their growth, it is not yet known whether prostate screening saves lives or whether treatment reduces disability and death from this disease.

The Centers for Disease Control and Prevention (CDC) does not recommend prostate cancer screening, but does recommend that men be provided with up-to-date information about screening, including the potential harms and benefits. Several organizations – including the American Cancer Society, American Urological Association, National Cancer Institute, and U.S. Preventive Services Task Force – recommend offering information about the potential harms and benefits of screening in order that men, their physicians, and their families can make informed decisions about screening.

For all of these reasons, it is important to educate the public and healthcare professionals about these issues concerning prostate cancer. Then, individuals will be able to make informed decisions about their prostate health in consultation with their doctors and families.

## PROSTATE CANCER IN NEW JERSEY

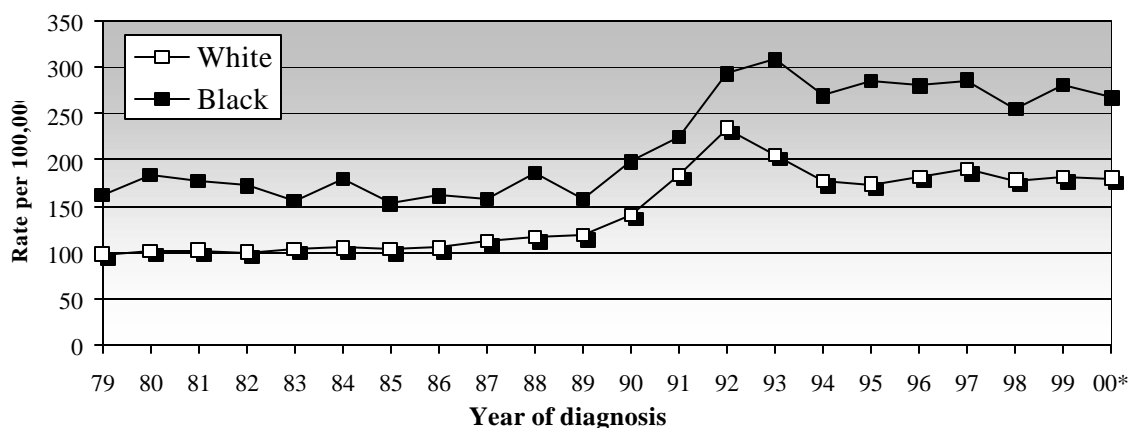
**Incidence.** The American Cancer Society estimates that among men in the U.S., 189,000 cases of prostate cancer will be newly diagnosed in 2002 (1). Among New Jersey men, about 5,700 cases of prostate cancer will be diagnosed in 2002 (1). In 2000\*, 192.2 men per 100,000\*\* were diagnosed with prostate cancer in New Jersey; the rate was 179.9\*\* among white men and 266.8\*\* among black men\*\*. The highest incidence of prostate cancer in New Jersey occurred in men between 70 and 79 for both whites and blacks (Figure 1). Black males have consistently had a higher incidence rate than white males in New Jersey, as well as in the nation (Figure 2). Between 1985 and 2000\*, the annual proportion of cases diagnosed in the early stages of the disease (either in-situ or localized) increased from about 61% in 1995 to about 76% in 2000 (7;8).



\*Incidence rates for year 2000 data from the New Jersey State Cancer Registry are preliminary.

\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. standard.

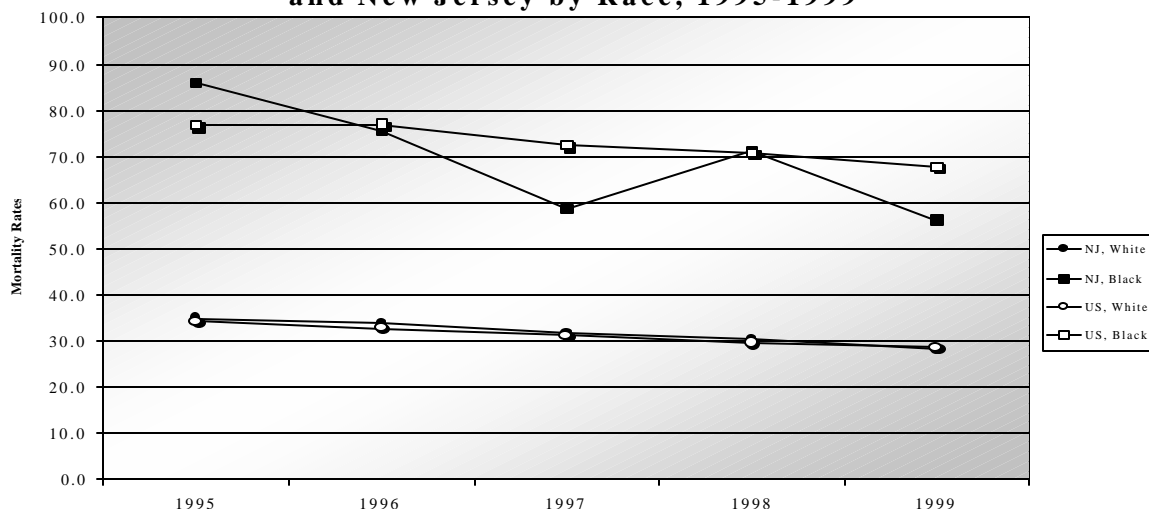
**Figure 2: New Jersey Prostate Cancer Incidence Rates  
by Race, 1979-2000\***



Source: NJSCR; \*Rates for the year 2000 data from the NJSCR are preliminary; Rates are per 100,000 and age-adjusted to the 2000 U.S. (5-year groups) Standard

**Mortality.** The American Cancer Society estimates that about 30,200 deaths due to prostate cancer will occur among men in the U.S. in 2002.(1) In New Jersey about 900 men will die of prostate cancer in 2002 (1). Prostate cancer mortality rates have decreased from 1995 to 1999; in whites in 1995 the New Jersey mortality rate was 35.0 per 100,000\*\* compared to 28.1 per 100,000 in 1999, for blacks the rate was 85.7 per 100,000 in 1995 compared to 56.2 per 100,000\*\* in 1999. This is consistent with decreases seen in the U.S. (9) (Figure 3).

**Figure 3: Prostate Cancer Mortality Rates for the U.S.  
and New Jersey by Race, 1995-1999**



Source: National Center for Health Statistics, Rates are per 100,000 and age-adjusted to the 2000 US population standard.

\*\*Rates are per 100,000 and age-adjusted to the 2000 U.S. standard.

Prostate Cancer Summits, most recently in April 2001, were held to gather New Jersey physicians, researchers, health professionals, patients, advocates and various organizations to address the serious healthcare crisis in prostate cancer. Three areas for action were identified for New Jersey: screening/early detection, public/professional/patient education, and research. Therefore, the Prostate Cancer Workgroup has used these three areas as a basis for addressing prostate cancer in this report.

Below is the Healthy New Jersey 2010 goal relating to prostate cancer.

**Healthy New Jersey 2010 Goal: Reduce the age-adjusted death rate of males from prostate cancer per 100,000 to 10.0 for total males, 10.0 for white males, and 25.3 for black males, ensuring that all efforts are appropriate culturally, linguistically, and at the proper literacy level, by 2010.**

**Table 1. Baseline data and projected target rates to decrease the death rate of males from prostate cancer.**

Populations	1998 Baseline Data	Target	Percent Change	Preferred 2010 Endpoint	Percent Change
Total age-adjusted	13.4	10.0	-25.4	6.2	-53.7
White age-adjusted	11.8	10.0	-15.3	5.4	-54.2
Black age-adjusted	32.0	25.3	-20.9	13.6	-57.5
Asian/Pacific Islander age-adjusted	#	#	#	#	#
Hispanic age-adjusted	#	#	#	#	#

Source: Healthy New Jersey 2010

#Data are statistically unreliable.

In support of the Healthy New Jersey 2010 goal for prostate cancer, the recommendations of the Prostate Cancer Workgroup are summarized below for the following five topic areas in priority order:

- Public Awareness and Education
- Patient/Client Education for Screening and Follow Up
- Access to Care
- Information for Medical Practitioners
- Research and Surveillance

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## GOALS, OBJECTIVES AND STRATEGIES

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### PUBLIC AWARENESS AND EDUCATION

As described earlier in this chapter, scientific consensus has not been reached on the effectiveness of prostate cancer screening in reducing deaths, and effective measures to prevent prostate cancer have not yet been determined. Education and early detection, therefore, represent the two prongs of our approach to addressing prostate cancer in New Jersey. Because there is no consensus on screening for this disease, the public must be educated on the risk factors for prostate cancer, the screening methods, and the options for treatment if cancer is found. The public should be educated about the pros and cons of prostate cancer screening to facilitate informed decision-making.

New Jersey is fortunate in that the New Jersey Cancer Education and Early Detection Program (NJCEED) has a state appropriation of \$900,000 to provide education and outreach to men regarding prostate cancer and to offer screening for the disease (Appendix E). If the offer to screen is accepted, men are then given the PSA and DRE screening tests.

It is hoped that education and the offer of screening and treatment services will be instrumental in fighting prostate cancer in New Jersey.

However, the NJCEED program only targets a specific population. Dissemination of prostate cancer information should be broadened to reach all New Jerseyans in order to more widely influence knowledge, attitudes, and practice related to adherence to prostate healthy behaviors, prevention, and early detection. Public education programs should include a systematic design and sustained delivery of methods and messages.

Educational and community-based programs can play an integral role in contributing to the improvement of health outcomes related to prostate cancer, specifically in high-risk populations. These programs, when developed to reach those outside of traditional healthcare settings, can be fundamentally important to enhancing health promotion and quality of life for New Jerseyans. Interventions that will elicit and ensure participation from populations at high risk for prostate cancer should be a high priority.

#### GOAL PR-1:

**To promote a public health message regarding prostate cancer screening and the benefits and risk factors of early detection, symptoms, and follow-up for normal and abnormal screening and treatment.**

#### Objective PR-1.1:

To increase public knowledge among **all** people about the risk factors associated with prostate cancer and the benefits of early detection, especially for men aged 40 years and older who are at high risk, men of African descent, and men with a family history of prostate cancer.

**Strategies:**

- (PR-1.1.1) Identify, or develop as needed, educational programs that comprehensively describe prostate cancer screening, the risk factors involved with screening, symptoms, follow-up, and treatment for all men, including participation in clinical trials.
- (PR-1.1.2) Ensure that the educational materials list the pros and cons of prostate cancer screening.
- (PR-1.1.3) Develop and test a standardized model informed consent form for prostate cancer screening.
- (PR-1.1.4) Identify, or develop as needed, educational programs that describe the issues related to barriers, myths, access, funding of prostate cancer screening, follow-up, and treatment for high-risk individuals, especially men of African descent.
- (PR-1.1.5) Identify and partner with community-based organizations for prostate cancer educational programs to further implementation.
- (PR-1.1.6) Provide prostate cancer educational programs throughout the age continuum through national, local, and statewide organizations, especially with high-risk populations.
- (PR-1.1.7) Develop a prostate cancer resource guide for New Jersey residents.
- (PR-1.1.8) Develop a distribution plan for the prostate cancer resource guide for New Jersey residents.
- (PR-1.1.9) Develop a communication plan for public education on prostate cancer.

**PATIENT/CLIENT EDUCATION FOR SCREENING AND FOLLOW-UP**

Although PSA levels alone do not supply doctors with sufficient information to distinguish between benign prostate conditions and cancer, the doctor will take the result of this test into account in deciding whether to check further for signs of prostate cancer. Men should discuss an abnormal PSA or DRE with their doctors, especially since it is not clear that all men need to be treated immediately for prostate cancer. Men should receive information regarding

possible risks and benefits of detecting and treating prostate cancer early. Men who ask their doctors should receive education and information about testing.

According to the American Cancer Society (10), many factors may cause an individual to refrain from seeking out available screening and educational programs. Personal beliefs and practices, lack of physician recommendation, and lack of access to medical care have all been identified as barriers to cancer screening. Low cancer screening prevalence is found particularly among adults who have

little or no access to medical care, are uninsured or underinsured, have lower education levels, live in rural areas, have language barriers, are members of ethnic minorities, or lack referrals from their physicians. Additionally, people with unhealthy lifestyle practices, such as smoking, are less likely to seek out cancer screening than those with healthy lifestyles.

To increase the number of New Jerseyans able to access screening, providing education is a first step. Increasing knowledge, improving physician recommendations, and creating access to affordable cancer screening tests are important ways to lower barriers to cancer screening. For example, when offices

and/or insurance companies use methods such as computerized reminders for screening appointments, screening rates tend to increase.

Currently, men in New Jersey who are eligible can be screened for prostate cancer through the NJCEED program (Appendix E). Yet additional efforts will be required to increase the number of men who seek out screenings. These efforts will demand improved collaboration among government agencies, private companies, non-profit organizations, healthcare providers, policy-makers, insurance companies, and the general public.

#### **GOAL PR-2:**

**To improve client/patient education about prostate cancer screening, risk factors, symptoms, follow-up, and treatment.**

#### **Objective PR-2.1:**

To increase knowledge among men with normal screening results about the need to annually discuss prostate cancer screening, using nationally recognized screening guidelines, with a medical professional.

#### **Strategies:**

- (PR-2.1.1) Investigate and distribute educational materials and resources that provide information on prostate health and screening. Develop these materials if needed.
- (PR-2.1.2) Ensure that distributed materials on prostate health and screening are up to date.
- (PR-2.1.3) Develop a communication plan for client/patient education on prostate cancer.



**Objective PR-2.2:**

To increase knowledge among men with screening abnormalities about the benefits and risks associated with nationally recognized prostate cancer diagnostic and treatment procedures by providing information and resources.

**Strategies:**

- (PR-2.2.1) Investigate available prostate cancer educational materials and resources that explain in detail the next steps to be taken following an abnormal screening, the available procedures, and the benefits and risks of each procedure. Develop these materials if needed.
- (PR-2.2.2) Distribute the above-mentioned materials to men with abnormal screening results for prostate cancer.

**ACCESS TO CARE**

One of the major barriers to cancer prevention and early detection is lack of access to proper screening. Although screening programs are available, access to care is a problem in medically underserved areas. Studies have shown that those with less than optimal access to care are generally ethnic minorities, unemployed, and have lower levels of education and income, usually below the poverty line (11).

In New Jersey, hassles within the healthcare delivery system have been identified as a major access issue, along with language and transportation barriers (11).

A variety of community-based organizations, especially faith-based organizations, specifically

design their programs for under-served populations. Local, state, and federal agencies also need to expand their programs to underserved populations.

Partnerships with healthcare providers are essential to facilitate prevention, and selected healthcare providers based on their location should target underserved populations. Establishment of a public announcement system available throughout the state that includes sites, times, availability of transportation, networking system, etc. is also essential. To improve access to care for prostate cancer, the Prostate Cancer Workgroup proposes the following goal, objective, and strategies.

**GOAL PR-3:**

**To increase access to prostate cancer services for all New Jersey men, including education, screening, treatment, and palliative care.**

**Objective PR-3.1:**

To increase the number of contacts, e.g., prostate cancer screenings, education, support groups, etc. made available by healthcare practitioners and advocates for targeted populations.

**Strategies:**

- (PR-3.1.1) Partner with community leaders / community-based organizations, including faith-based organizations, on prostate cancer education and screening programs to create incentives that attract underserved populations.
- (PR-3.1.2) Identify underserved populations in need of prostate cancer education and screening using credible data available through local, state, and federal agencies.
- (PR-3.1.3) Identify prostate cancer education and screening services in convenient sites or areas within communities.
- (PR-3.1.4) Develop strategies to empower significant others to encourage males to seek prostate cancer education and screening services.
- (PR-3.1.5) Provide advocacy services to help clients with prostate cancer navigate the healthcare system.
- (PR-3.1.6) Develop strategies to encourage payors to support community-based prostate cancer prevention services since early detection may be more cost effective.
- (PR-3.1.7) Partner with community-based organizations to address language, education, literacy, cultural, and economic barriers to receipt of prostate cancer education and screening services.
- (PR-3.1.8) Provide transportation to prostate cancer treatment services.
- (PR-3.1.9) Partner with community-based organizations to develop and offer culturally relevant programs located within easily accessible community sites, e.g., take prostate cancer education and screening programs to community events, bring programs to the people.
- (PR-3.1.10) Develop funding sources through government agencies, insurance and pharmaceutical companies, and foundations to assist in finding ways to increase access to prostate cancer education and screening services.

## **INFORMATION FOR MEDICAL PRACTITIONERS**

Prostate cancer is characterized by a wide range of treatment options depending on a patient's age, overall health, status of the cancer, and personal choice. In addition, knowledge about the disease and its treatment is constantly evolving. Physicians, particularly primary care doctors, may find it difficult to remain alert to new developments and subsequently advise or treat individual patients in an efficient and comprehensive manner. Various sources of information on prostate cancer are available nationwide but are not universally accessible. For example, Continuing Medical Education (CME) category 1 and 2 courses in prostate cancer are not always open to primary care physicians. A clearinghouse of data and information about prostate cancer and its treatment (located in and with data specific to New Jersey) would be advisable and should be located on the internet. The clearinghouse

should contain such information as a list of practicing clinicians (primary care physicians, urologists, oncologists, radiation oncologists, pathologists) in the state with medical biographies; a database of studies on both conventional and integrative treatments; and studies/information on screening tests. Furthermore, the clearinghouse should maintain a calendar of educational opportunities in the state for medical practitioners. Educational opportunities should include conferences, public, legislative, and government forums, as well as continuing education classes offered by medical schools and institutions, medical societies, and private entities. The calendar would serve as an additional source of information for practitioners who wish to keep pace with developments in prostate cancer and its treatment. The availability of this information, which may be included in medical publications and disseminated via professional organizations, should be forwarded to all primary care and specialty physicians in the state.

### **GOAL PR-4:**

**To improve professional education on symptoms, risk factors, screening, and follow-up care for prostate cancer.**

#### **Objective PR-4.1:**

To provide information and resources to medical professionals so they may discuss the pros and cons of prostate cancer screening with their patients and so that patients and providers together can make informed decisions about screening.

#### **Strategies:**

- (PR-4.1.1) Develop and implement an up-to-date database of prostate cancer educational opportunities for practitioners.
- (PR-4.1.2) Develop a communication plan for provider education on prostate cancer.

**Objective PR-4.2:**

To provide information and resources to medical providers for prostate cancer follow-up care for high-risk and general populations.

**Strategies:**

- (PR-4.2.1) Develop and implement an up-to-date database of prostate cancer educational opportunities for the public.
- (PR-4.2.2) Develop a communication plan for the database for prostate cancer.

**RESEARCH AND SURVEILLANCE**

The American Cancer Society estimates that in New Jersey, 5,700 men will be diagnosed with prostate cancer and 900 will die of the disease in 2002. A significant decline in the number of deaths from prostate cancer has occurred since 1996, while the number of new cases has declined slowly. However, the burden is not equal. Among black men the toll of prostate cancer is particularly high, with a disease incidence approximately 50% higher than among white men. In addition, black men tend to experience the disease at an earlier age than white men, are diagnosed at more advanced stages of the disease, and die at a rate twice

that of white men (1). Men of all races with close relatives with prostate cancer are also at high risk for the disease.

Currently, researchers at the Cancer Institute of New Jersey are studying the effects of alternative medicine, such as herbal medicine, in relation to prostate cancer (12). However, additional science- and evidence-based research and surveillance will provide the tools to direct resources to those with the greatest need and for whom intervention will bring the highest gains. By assessing the specific rates of prostate cancer, and stage at diagnosis by geographic and demographic information, specific interventions can be designed to address the needs identified.

**GOAL PR-5:**

**To expand a research agenda specific to prostate cancer issues in New Jersey.**

**Objective PR-5.1:**

To develop a plan to incorporate men, in demographic groups that are underrepresented, in prostate cancer screening and clinical trials.

**Strategies:**

- (PR-5.1.1) Identify and develop community leaders as intermediaries between organized medicine and the individual client concerned about prostate cancer.
- (PR-5.1.2.) Develop outreach programs with community leaders to improve client participation in screening and clinical trials.
- (PR-5.1.3) Increase the quality and the amount of information the patient receives to make an informed consent to prostate cancer screening.
- (PR-5.1.4) Partner with the New Jersey Commission on Cancer Research to encourage researchers to seek out grants in prostate cancer research.

**Objective PR-5.2:**

To support the evaluation of complementary alternative medicine (CAM) in relation to prostate cancer e.g., herbal preparations, vitamins, etc.

**Strategy:**

- (PR-5.2.1) Identify complementary alternative medicine (CAM) interventions being utilized by New Jersey residents for prostate cancer. Differentiate those patients involved in clinical trials.

**Objective PR-5.3:**

To facilitate the collaboration between institutions providing prostate cancer clinical trials and underrepresented populations.

**Strategies:**

- (PR-5.3.1) Encourage the physicians of underrepresented populations to refer their prostate cancer patients to clinical trials in New Jersey.
- (PR-5.3.2) Encourage the physicians of underrepresented populations to participate directly in clinical trials for prostate cancer in New Jersey.
- (PR-5.3.3) Educate physicians about clinical trials for prostate cancer so that this information can be disseminated to men who may be eligible to participate.

**Principal Change Agents:** The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: PR-1.1.1; PR-1.1.2; PR-1.1.3; PR-1.1.4; PR-1.1.5; PR-1.1.6; PR-1.1.7; PR-1.1.8; PR-1.1.9; PR-2.1.1; PR-2.1.2; PR-2.1.3; PR-2.2.3; PR-2.2.4; PR-3.1.7; PR-3.1.8; PR-3.1.9; PR-3.1.10; PR-4.1.1; PR-4.1.2; PR-4.2.1; PR-4.2.1; PR-5.1.1; PR-5.1.3; PR-5.1.4; PR-5.2.1

New Jersey Department of Health and Senior Services, New Jersey Cancer Education and Early Detection (NJCEED): PR-1.1.1; PR-1.1.2; PR-1.1.3; PR-1.1.4; PR-1.1.5; PR-1.1.6; PR-1.1.7; PR-1.1.8; PR-1.1.9; PR-2.1.1; PR-2.1.2; PR-2.1.3; PR-3.1.1; PR-3.1.2; PR-3.1.3; PR-3.1.4; PR-3.1.5; PR-3.1.6; PR-3.1.7; PR-3.1.8; PR-3.1.9; PR-3.1.10

## PROSTATE

PROSTATE								
GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Promote public health message	1.1: Increase public knowledge among all residents	PR-1.1.1						
		PR-1.1.2						
		PR-1.1.3						
		PR-1.1.4						
		PR-1.1.5						
		PR-1.1.6						
		PR-1.1.7						
		PR-1.1.8						
		PR-1.1.9						
2: Improve patient education	2.1: Increase knowledge among patients with normal screening results	PR-2.1.1						
		PR-2.1.2						
		PR-2.1.3						
	2.2: Increase knowledge among patients with screening abnormalities	PR-2.2.1						
		PR-2.2.2						
3: Increase access to services	3.1: Increase number of contacts	PR-3.1.1						
		PR-3.1.2						
		PR-3.1.3						
		PR-3.1.4						
		PR-3.1.5						
		PR-3.1.6						
		PR-3.1.7						
		PR-3.1.8						
		PR-3.1.9						
		PR-3.1.10						
4: Improve professional education	4.1: Provide information/resources to medical providers regarding screening	PR-4.1.1						
		PR-4.1.2						
	4.2: Provide information/resources to medical providers regarding follow-up care	PR-4.2.1						
		PR-4.2.2						
5: Expand research agenda	5.1: Develop plan for underrepresented groups regarding screening and clinical trails	PR-5.1.1						
		PR-5.1.2						
		PR-5.1.3						
		PR-5.1.4						
	5.2: Support evaluation of complementary alternative medicine	PR-5.2.1						
		PR-5.3.1						
	5.3: Facilitate collaboration regarding clinical trials	PR-5.3.2						
		PR-5.3.3						
			Target Completion Date					

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